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## **Life events in senile dementia.**

Orrell, Martin William

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# Life Events in Senile Dementia

Thesis submitted for the degree of  
Doctor of Philosophy (Psychiatry)

**MRC Social and Community Psychiatry Unit**

**Institute of Psychiatry**

**University of London**

1994

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## **ABSTRACT**

This study investigated the hypothesis that recent life events are related both to acute deterioration of senile dementia and to the patient's presentation to services, and that this may relate to life events involving change in routine and environment. The study was a case-control comparison. Seventy patients with senile dementia and their informants were interviewed about life events in the six months prior to their admission to a psychogeriatric unit. Two control groups and informants were also interviewed: a) 50 fit elderly, matched for age and sex from a general practice list; b) 50 elderly with senile dementia in the community. The principal instruments were the Geriatric Mental State Schedule, and the Bedford College Life Events and Difficulties Schedule. There was found to be no difference in the proportion of subjects in each group who had a life event in the six months preceding admission. However, the dementia patients had an excess of life events in the four weeks before the date of deterioration compared to the control groups. This association no longer held when dependent events were excluded. Dementia sufferers with depression had significantly more independent, severe threat life events in the previous six months compared to those without depression. The dementia patient group were significantly more likely to have had independent life events which disrupted their daily routine. New scales for rating life events for changes in routine and environment were highly reliable when used by new raters after brief training. In dementia sufferers, life events which disrupt routine appear to contribute to deterioration leading to admission, whereas threatening life events are strongly associated with depressive symptoms. This has implications for understanding the social influences on senile dementia. It should also help clinicians to evaluate the various influences on a patient's clinical condition.

## **SUMMARY**

The introduction describes how acute deterioration in senile dementia cannot easily be explained by conventional biological models of the dementing process. It notes that dementia patients are sensitive to changes made in their routine and environment, and that relocation can lead to disorientation, behavioural disturbance and higher mortality. Life events can contribute to psychiatric illness and have been linked with decline in physical health or death. Senile dementia patients are sensitive to changes in their routine and environment so they may be vulnerable to life events which could also cause distress. These factors might result in the patient's coping skills being overloaded, leading to a deterioration in cognition, mood and behaviour necessitating hospital admission. Contemporary theories of social psychology, neuroendocrinology and neuronal ageing can be used to produce a model showing how stress and environmental change might contribute to the dementing process. This study investigated the hypothesis that recent life events are related both to acute deterioration of senile dementia and to the patient's presentation to services and that this deterioration may particularly relate to life events involving change in the patient's social routine and perceptual environment.

The study was a case-control comparison. Seventy patients with senile dementia and their informants were interviewed about life events in the six months prior to their admission to a psychogeriatric unit. Two control groups and informants were also interviewed: a) 50 fit elderly subjects, matched for age and sex from a local general practice; b) 50 elderly subjects with senile dementia in the community drawn from attenders and the waiting lists of local dementia day centres. The instruments used were the Geriatric Mental State Schedule, Bedford College Life Events and Difficulties



Schedule, and the Clifton Assessment Procedure for the Elderly (behavioural schedule).

Information on psychiatric history, physical health, and social situation was also collected. The psychiatric correspondence prior to the admission was rated by an observer blind to the outcome to determine the relative influences of physical, psychiatric, and social factors on the decision of the psychiatrist to admit.

There was no difference in the proportion of subjects in each group who had had a life event in the six months preceding admission. However, the dementia patients had had an excess of life events in the four weeks before the date of deterioration compared to the control groups. This association no longer held when events which the individual could have precipitated (dependent events) were excluded. For both dementia groups, subjects with depressive symptoms were significantly more likely to have had independent, severely threatening life events in the past six months compared to those with no depressive symptoms. This association held when other variables such as age, sex and degree of cognitive impairment were controlled for, using a logistic regression analysis. In the dementia patient group, anxiety symptoms were also associated with recent life events. The subjects in the dementia patient group were significantly more likely to have experienced life events which disrupted their daily routine ( $p < 0.0004$ ), and this association remained when dependent events were excluded. The new scales for rating life events for changes in routine and environment were found to be highly reliable when used by new raters after brief training. A three year follow up of the first 60 (of 70) in the dementia patient group was also carried out.

The results suggest that there is an excess of severe threat life events before deterioration in dementia, but that this excess can largely be accounted for by life events which the individuals themselves could have precipitated during the deterioration process. However, life events which disrupt routine appear to be able to contribute to deterioration leading to admission. This has implications for our understanding of the social influences on dementia, and thus could be an important consideration in clinical practice. With the high prevalence of depressive symptoms in the elderly with dementia, the finding that such symptoms appear to be precipitated by life events is particularly important. This indicates that dementia sufferers can become distressed by stressful events and may experience depressive and anxiety symptoms as a result. The study develops our understanding of how stress and life change can affect people with senile dementia. It should also help clinicians who are trying to evaluate the various potential influences on a patient's clinical state.

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# INTRODUCTION

## *1.0.0 Overview*

This section will begin with an overview of the epidemiology and aetiology of senile dementia and a discussion of the historical roots of the concept. In particular, it will examine why the disease process has been widely regarded as the exact manifestation of an exclusively organic form of degeneration of the brain, despite the evidence to suggest that clinical manifestations of dementia are responsive to environmental influences and that environmental change may even be linked to neurotransmitter changes. The importance of research into life events will be discussed with particular reference to the elderly and the mentally ill. In addition, possible relationships between stress, ageing and abnormalities of the hypothalamo-pituitary-adrenal axis will be reviewed with reference to the potential links between the neuroendocrine system and dementia.

Lastly, the theoretical foundations of this study will be developed, with respect to the relative biopsychosocial influences on, senile dementia, the process of deterioration, and hospital admission.

The definition of dementia is taken as *'an acquired global impairment of intellect, memory and personality, but without impairment of consciousness'* (Lishman, 1987).

'Senile dementia' is used to describe those dementias of the elderly which are fundamentally due to a primary degeneration of the brain. By far the most common forms of this are Alzheimer's disease, Multi-infarct dementia, or some combination of the two.



### ***1.1.0 The epidemiology of senile dementia***

Senile dementia affects more than 5% of the over 65s (Bergmann, 1985) and epidemiological studies show that its prevalence is directly related to age. For example, only 2% of the population between the ages of 65 and 70 are affected, whereas about 20% of people over the age of 80 suffer from it (Royal College of Physicians, 1981). This is particularly significant, since the number of people over 75 will increase dramatically into the 21st century. It is estimated that 570,000 people in Britain today suffer from Alzheimer's disease (Rossor, 1987). The life expectancy of those suffering from senile dementia appears to be increasing (Blessed and Wilson, 1982), and paradoxically it is the younger patient with pre-senile dementia who is more likely to die from it, in contrast to the more elderly patients, who frequently die from other causes. The vast majority of those suffering from senile dementia are not in institutions but living in the community (Kay et al., 1964). However, before death occurs the patient usually becomes progressively more mentally incapacitated and dependent over a period of several years. This places an enormous burden on the carers and on the resources of the health service (Eagles and Gilleard, 1984). As Pitt (1987) has noted: *'old age is a time when one infirmity after another is added to such vicissitudes as widowhood and dwindling life expectancy, but none matches dementia in its devastation of the capacity for self care, its erosion of relationships and its demands on the family and the community'*.

### ***1.20 The conceptual history of dementia***

To understand why senile dementia has often been viewed as a purely organic illness, immutable in the face of any social or psychological influence, it is appropriate to

consider the conceptual history of the disorder. In bygone days, growing old was comparatively rare: the average life span of a subject of the Roman Empire was less than 30 years, and perhaps only 3% of the population lived to be 65. Even as recently as 1840, in England, most perished before their 45th birthday (Mahendra, 1984). Although Cicero observed both the physical and mental effects of senility, Celsus in the 1st Century AD was probably the first to use the term 'dementia'. By the time of the Byzantine physician, Paul of Aegina in the 7th century AD, some authorities agreed that mental and physical deterioration was not an inevitable consequence of ageing, but could be the result of an underlying pathological process. Paul of Aegina described the problems of loss of memory and reason in his writings, but it is unclear whether or not he was referring specifically to senile dementia (Mahendra, 1984).

Up to the Renaissance period, the idea of decrepitude and melancholia being an inexorable consequence of old age was still commonplace. It was not until the 19th century that a clear distinction was made between the cognitive impairments of dementia, and mental handicap (Mahendra, 1984), although Willis in 1684 noted that the two were separate conditions with different causes (Berrios, 1987). During the 19th century the 'cognitive model' of dementia was formed, the key features being deficits in recent memory and in judgement.

In 1907 Alois Alzheimer described a case of pre-senile dementia with distinctive neuropathology (Mahendra, 1984), and Kraepelin suggested it be named after him. The following five years led to a spate of some 50 papers being published on the topic. Although Alzheimer regarded the disease as different from arteriosclerotic dementia,



Kraepelin remained unconvinced (Mahendra, 1984). Senile plaques and tangles characteristic of Alzheimer's disease (AD) could also be identified in the post-mortem brains of elderly people who had not suffered from AD. This contributed to speculation that those with other manifestations of mental illness in old age, such as depressive or paranoid symptoms, were actually suffering from milder degrees of senile dementia (Roth, 1955). Senile dementia in itself was often viewed as a degenerative process as a result of the morbid ageing of the brain. It was not until Roth's seminal paper in 1955 that an appropriate distinction founded on clinical assessment and differing outcome was made between senile dementia and the other mental disorders of old age. The relative success in defining the pathology in senile dementia may have impeded not only a more clinical classification, but also progress in diagnosis and management. Even so, there is great diversity in the neuropathology and clinical manifestations (Förstl et al., 1993).

In general adult psychiatry, the major groups of illnesses such as the neuroses and the functional psychoses have had a very different conceptual history. After World War One the relative ineffectiveness of physical treatments for the epidemic of 'shell shock' (which had been widely regarded as a purely organic disorder), in comparison with the psychological therapies, led not only to a greater acceptance and discussion of Freud's theories, but also to a better understanding of neurosis in general. Conversely, it was the success of the new drug treatments for schizophrenia and manic-depressive illness in the 1950s which contributed to the search for psychosocial explanations as to why similar patients had differing outcomes. This success also led, in part, to the rejection of many of the less substantial previous theories and therapies. In the functional



psychiatric disorders it therefore seems to have been partly the availability of treatment which motivated a reappraisal of the possible factors predisposing to, precipitating, and perpetuating an illness. As late as 1960, the standard British psychiatric textbook considered dementia to be chronic and irreversible (Mahendra, 1984), but later in the decade, advances in the treatment of conditions such as hydrocephalus and systemic disorders helped alter that view.

### ***1.2.1 Aetiology of senile dementia***

As a result of worldwide research, over the last twenty years the revolution in medical technology has contributed to significant advances in the understanding of the pathological basis of dementia, particularly of Alzheimer's disease and multi-infarct dementia. Apart from the well established finding that Alzheimer's disease increases with age (Wilcock and Jacoby, 1991) and may be slightly increased in females (Amaducci and Lippi, 1992; Livingston and Hinchcliffe, 1993), the search for causative factors which could account for the majority of cases has been less promising. The neuropathological changes associated with Alzheimer's disease are also present in the normal elderly as a function of ageing. As a result of this finding it has been proposed that Alzheimer's disease is a form of accelerated brain ageing (Brayne and Calloway, 1988; Von Dras and Blumenthal, 1992). There has been some speculation that poor education may increase the risk of developing dementia possibly by reducing the level of brain reserve so that a lesser degree of pathology could lead to a syndrome of dementia (Amaducci and Lippi, 1992). Recent work suggests that education may be an important protective factor for Alzheimer's disease (Friedland, 1993) possibly by modifying individual thresholds for decompensation and survival

time (Whalley, 1992; Evans, 1992). The mechanism for this might be through increasing neocortical synaptic density (Katzman, 1993). Synapse loss is one of the key pathological changes in AD and this suggests a mechanism whereby late life cognitive activity might also reduce risk or delay onset (Katzman, 1993).

## **Genetic**

Alzheimer's disease (AD) comprises at least 50% of all forms of senile dementia, and is estimated to contribute to another 20% or more of cases. Those with a family history of the illness are known to be at a higher risk of developing the disease (Heston et al., 1981). A population study by Larsson et al (1963) indicated that there was a fourfold increase in risk of morbidity in the siblings of those with the disorder. The early onset form of AD is rare, but is associated with greater severity and a higher level of heritability (Wright and Whalley, 1984). In this group, the disease segregates as an autosomal dominant trait in a few large pedigrees (Nee et al., 1983). However, Pratt (1970), in his review, concluded that a polygenic form of inheritance was more likely, since only 10-15% of AD cases were familial, the remainder being sporadic in type.

The discovery that those with Down's syndrome are at particularly high risk of developing Presenile Alzheimer's disease (Olsson and Shaw, 1969) has led to two other questions. First, is Chromosome 21 a possible site for the AD gene, and secondly, could maternal age be an important factor in the development of Alzheimer's disease? A number of studies have shown maternal age to be significantly related to the risk of developing AD (Cohen and Eisdorfer, 1984; Whalley et al., 1982), but other



studies demur (Ferini-Strambi et al., 1990; Dewey et al., 1988). A collaborative re-analysis of four case control studies (Rocca et al., 1991) found a consistently increased risk of Alzheimer's disease for maternal age 40 and over (relative risk 1.7; 95% confidence interval: 1.0-2.9) especially for women and for sporadic cases. Maternal age may therefore be a risk factor, but further studies are needed.

It is now established that all sufferers from Down's syndrome develop characteristic Alzheimer's pathology if they survive into their fifth decade. A genetic locus for early-onset AD has been identified on the proximal segment of the long arm of Chromosome 21 in certain families (St George Hyslop et al., 1987). Around the same time, the gene for amyloid (the A4-amyloid gene), which is found in the neuritic plaques characteristic of AD, was localised to the same region of the same chromosome (Goldgaber et al., 1987). It now seems that the proximity of the two loci was probably coincidental, and speculation that a mutation in the A4-amyloid gene (Delabar et al., 1987) was responsible for causing AD was rejected (Van Broeckhoven et al., 1987). Recently, the locus for the gene of a rare familial variety of AD has been identified on chromosome 21 (Goate et al., 1991) and this gene, which codes for Amyloid Precursor Protein (APP), was shown to have a point mutation in affected individuals, suggesting a primary role in the development of Alzheimer's in certain families. Despite doubts expressed over the past few years, studies of the origin and effects of cerebral amyloid deposition continue to provide clues to early events in Alzheimer's disease (Selkoe, 1991). During ageing, humans develop extracellular deposits of  $\beta$ /A4 protein called preamyloid, or diffuse plaques which are largely filamentous and don't have the dystrophic neurites (axons and dendrites) that surround



the filamentous amyloid cores of mature plaques. In Alzheimer's disease a much greater number of diffuse  $\beta$ /A4 amyloid deposits occur and many of these have become filamentous with structurally altered neurites accompanied by neurofibrillary tangles made of tau protein. This Amyloid Precursor Protein (APP) appears to be largely responsible for the widespread development of Amyloid plaques. The discovery of a mutation of the gene coding for APP in a handful of families with an autosomal dominant form of Alzheimer's disease indicates that amyloidogenic processing of  $\beta$ APP precursor protein can precede all other manifestations of Alzheimer's and thus be truly causative of the disorder (Selkoe, 1991). But because plaques and tangles occur as part of the normal ageing process, the distinction between Alzheimer's disease and ageing is quantitative rather than qualitative, suggesting that in some ways it may be an *acceleration* of ageing. Research in Alzheimer's disease (AD) may throw light on some of the subtle changes in cognition which occur with ageing, but the overall picture remains inconclusive and merits further enquiry. Mullan (1993) in a recent review of the molecular biology of AD concluded that '*we are a considerable distance from a unitary hypothesis of AD pathogenesis. As the known causes of AD (APP mutants and Down's syndrome) are few and possibly atypical, it is unsurprising that a robust hypothesis explaining the more common forms of the disease is not forthcoming*'.

### **Season of birth**

Since season of birth has been suggested as a risk factor in other psychiatric and neurological disorders such as schizophrenia and Parkinson's disease, Philpot et al. (1989) studied it in relation to Alzheimer's disease. They found that in Alzheimer's

sufferers without a family history of dementia there was a significant excess of first quarter births compared to the expected birth rate derived from published census data. One of the theories put forward for the results was that being born in winter was more hazardous in terms of risk of infectious agents, extremes of temperature, nutritional deficiencies or obstetric complications. But the authors conclude that their finding is not necessarily of aetiological significance and that larger studies need to be done.

### **Immunological**

Immune mechanisms decline with ageing, and it has been suggested that AD could be an acceleration of that process (Nandy, 1978). Amyloid is believed to be deposited in the tissues under conditions of altered immunity and high levels of IgG have been noted in the amyloid fibrils in the plaques (Ishii and Haga, 1976). Significant correlations between tests of cognitive function and levels of serum immunoglobulin were found in a comparison between inpatients with AD and age-matched controls (Eisdorfer et al., 1980; Cohen and Eisdorfer, 1980). Heston et al. (1981) showed an increased incidence of immune-system disorders in the relatives of patients with Alzheimer's disease, but in a review Henschke (1987) concluded that despite the advances in immunological research methods, no worthwhile clue to any immune mechanism of pathogenesis currently exists in Alzheimer's disease.

### **Aluminium**

The discovery that high aluminium levels in the dialysate were responsible for the form of dementia occurring in some renal dialysis patients fuelled speculation that aluminium might be a causative agent in AD. In addition, work by Crapper et al.



(1976; 1978) demonstrated not only that elevated aluminium levels were present in brain in AD, particularly in the neurofibrillary tangles, but also that tangles could be induced by adding aluminium to cultured human foetal cortical neurones. However, it has now been shown that these tangles are straight and not helical like those in AD. The age disparity between the controls (mean 47) and the demented group (mean 68) in Crapper's 1976 study may provide an explanation, since a study by McDermott et al. (1979) found that brain aluminium concentrations increase steadily with age. In an epidemiological study which showed an increase in the incidence of Alzheimer's disease associated with a higher level of aluminium in drinking water there was no clear dose-related trend (Martyn et al., 1989), and the results are unconvincing because there is a far higher intake from a normal diet (Wilcock and Jacoby, 1991). The present consensus of opinion holds that aluminium has no primary role in the genesis of dementia but merely accumulates as a result of ageing or damage to neurones (Lishman, 1987).

### **Transmissible agents**

Since both Kuru and Creutzfeld-Jakob disease are both caused by a transmissible virus (Gajdusek, 1977), this has prompted the search for a similar agent in Alzheimer's disease. However, extensive attempts to demonstrate the transmission of AD in the laboratory have not succeeded, and the few studies which did suggest a link have been methodologically unsound and not confirmed by later replication. More recently, it has been argued that an infectious aetiology may be possible in genetically susceptible individuals (Wisniewski et al., 1984) by comparison with the prion spongiform encephalopathy scrapie. However, although the theory is interesting, scrapie is not



directly comparable, and no convincing evidence was presented to suggest a prion etiology for Alzheimer's disease (AD).

### **Head injury**

Several case-control studies have found previous head trauma to be a risk factor significantly associated with the later development of Alzheimer's disease (Heyman et al., 1984; Mortimer et al., 1985; Graves et al., 1990). It may also hasten the onset of AD (Gedye et al., 1989) since patients with a history of severe head injury before the age of 65 showed an onset of symptoms at an earlier age compared to AD patients without head trauma. However, other studies have found a higher rate of head trauma among cases compared to controls (Chandra et al., 1987a) but the difference did not reach statistical significance. And some studies have found no association between AD and head trauma (Soininen and Heinonen, 1982; Ferini-Strambi et al., 1990). In particular, a follow up of 821 persons who had a previous history of head trauma with presumed brain injury between 1935 and 1974 (Williams et al., 1991) found no increase in the risk of developing AD with a standardised morbidity ratio (SMR) of 1.06 (an SMR of 1.00 denotes equivalent risks for both groups). However, a re-analysis of the data from 11 case-control studies, performed by the EURODEM Risk Factors Research Group (Mortimer et al., 1991) showed a pooled relative risk of 1.82, suggesting head trauma was a risk factor. Stratified analyses suggested that there was a stronger association in males and those without a positive family history of dementia. Contemporary opinion suggests that previous severe head injury is a probable but not confirmed risk factor for the development of Alzheimer's disease (Amaducci and Lippi, 1992). In any case, head injury alone could not explain the majority of cases.

## **Nerve Growth Factor**

Nerve Growth Factor has also been studied, since in some cases it appears to be associated with abnormal plaques (Wilcock & Jacoby, 1991) and may have a role in the development of Alzheimer's disease (Everall & Kerwin, 1990). Stress might play a role in the control of Nerve Growth Factor because Lindholm et al. (1991) have demonstrated that glucocorticoids can downregulate the expression of Nerve Growth Factor by interfering with transcription. This result is all the more interesting because of the findings of a recent study which suggested that the action of Nerve Growth Factor was influenced by environmental change, and that this may have implications for the importance of adequate environmental stimulation in Alzheimer's disease and the associated behavioural and neurochemical deficits (Mohammed et al., 1990). Neurotrophin expression is governed by physiological activity (Gall, 1992), lending credibility to the old adage "use it or lose it" (Perry and Perry, 1993).

## **Depression**

Although Pitt (1993) in his review concludes that there is little convincing evidence that depression is a risk factor in the genesis of dementia there have recently been several case-control studies with adequate methodology which suggest that a previous history of depression may predispose to later development of Alzheimer's disease. Amaducci and Lippi (1992) have pointed out the difficulties of research in this area because the diagnostic clinical criteria for AD (McKhann et al., 1984) used in many studies could make it difficult to study previous psychiatric disorders. However, three case control studies (Shalat et al., 1987; Broe et al., 1990; French et al., 1990) found that a past history of depression was significantly more frequent in AD cases compared



to controls. Moreover, the meta-analysis of case-control studies by the EURODEM Risk Factors Research Group found an association with a history of depression in late-onset cases of AD (Jorm et al., 1991). This result was consistent even for depressive episodes occurring more than 10 years before AD onset, indicating that the link between depression and AD was not a reflection of depressive symptoms due to the early stages of AD.

In conclusion, the search for causative factors which can account for the majority of cases of Alzheimer's disease is far from over. In the current state of knowledge, no risk factors can be considered both necessary and sufficient for the development of the disorder.

### **Multi-infarct dementia**

Risk factors for Multi-infarct dementia (MID) are principally, age, family history, stroke, hypertension, cardiac dysfunction, serum cholesterol, diabetes and smoking (Peisah et al., 1993). Roth (1986) suggests that in some forms of dementia, sub-threshold degrees of both AD and MID are present, either of which, if present individually would be insufficient to cause the clinical syndrome. Pathological evidence strongly supports this view. The threshold theory is also supported by the dementia which occurs in a proportion of ex-boxers five to ten years after the end of their career, having been symptom free until then. Thus, although the traumatic damage at the time is finite, the early stages of ageing further diminish the brain's functioning capacity, the threshold level (of neuronal death) is reached and dementia ensues. The effects of psychosocial stress have not been studied with respect to Multi-



infarct dementia, but it is possible that they may be important because such stresses may contribute to other types of vascular disease such as hypertension, myocardial infarction (Connolly, 1976) and stroke (House et al., 1990).

In his review of the social psychiatry of late life, Henderson (1990) emphasised the need both for a continued search for clues to the aetiology of Alzheimer's disease, and for an intensive theory-driven investigation of the social environment in mental disorders in the elderly. This study develops a theory-driven investigation of the social environment in senile dementia.

### ***1.2.2 Deterioration in dementia: failure of current theoretical models***

Frequently in senile dementia there is an abrupt deterioration in physical, cognitive or behavioural function (Patterson & LeClair, 1989) which is not necessarily a reflection of recent pathological deterioration of the brain but may be due to psychiatric, physical or social causes (Bergmann, 1985). The suggested social causes included change in the individual's living environment such as relocation, a change of carer, or personal difficulties of the carer.

Common aspects of acute deterioration (Lam et al., 1989; Rockwood et al., 1991) such as aggression and wandering (which are also associated with admission) do not fit neatly into models of the dementia process in terms of neuropsychological and neuropathological change. In itself, severity of dementia may correlate well with the degree of pathology, and cortical atrophy measured by CT scan, but there is a considerable overlap with the normal elderly population, and clinical diagnosis remains

paramount (Blessed et al., 1968; Jacoby and Levy, 1980; Bird et al., 1986). Even in Alzheimer's disease, studies have only shown the accuracy of clinical diagnosis to be about 70-80% (Sulkara et al., 1983; Walton, 1992). Even so, there are no convincing models which can account for the quality or quantity of symptoms in many dementia cases. In particular, acute episodes of cognitive and behavioral deterioration cannot be adequately explained by conventional biological models of the dementing process.

It is evident therefore that the present state of knowledge regarding the aetiology of senile dementia remains inadequate. None of the risk factors, either alone or in combination, is necessary for dementia to occur, and no current theory provides a sufficient explanation for the process and course of senile dementia. In these circumstances, it is surprising that so little is known about possible social or environmental risk factors. A recent study suggested that environmental risk factors may be important (Copeland et al., 1987). It has even been proposed that low levels of social stimulation may initiate or accelerate the process of dementia, particularly of the Alzheimer type (Cosin et al., 1958; Whitehead, 1984). The importance of social factors on the process of mental deterioration and admission in the elderly is well recognised, and a study by Lewis (1943) suggested that social factors cause a rapid increase in admissions during a time of great social upheaval such as the outbreak of war. Lewis concludes:

*'Failure to retain a place in the community, to be a member of a family, to have an appreciated share in the life of some household or working group has been common in the patients studied: this defect of social integration is*



*powerfully adverse to mental health - it could hardly be otherwise. It has in some of these cases been the outcome of a wayward and difficult personality; but more often it has been an unavoidable consequence of the narrowed circle, the bereavement and the incapacity for forming new habits and associations which often characterise old age.'*

In view of Lewis's work more than forty years ago it is surprising that there has been little investigation of psychosocial causes of deterioration in dementia.

### ***1.3.0 Psychosocial processes in dementia and ageing***

As early as the 2nd century BC, poets and philosophers who ascribed to the practice of mental hygiene, mused that an active mental life might forestall or delay the enfeeblement of old age (Rosen, 1961), and Cicero in 'De Senectute' implied that old men preserve their intellects if they preserve their interests, i.e. 'the use it or lose it' hypothesis (Pitt, 1993). More recently, in the field of neurobiological research there has been a whole series of articles debating whether the brain was more likely to degenerate as a result of over-use or under-use, in other words the 'wear and tear versus 'use it or lose it' argument. Swaab (1991) argued that activation of nerve cells within the physiological range seems to lead to '*maintenance of neurons during aging and Alzheimer's disease possibly by preferentially stimulating the action of protective mechanisms such as DNA repair*'. Swaab points out that several studies have shown that elderly rats exposed to an enriched environment have increased cortical thickness and weight, increased dendritic branching and improved general performance compared to controls in a non-stimulating environment. In humans dendritic growth continues



well into the senium (Buell and Coleman, 1979), indicating that environmental stimulation might play an important role in providing a higher level of brain reserve which could therefore delay dementia onset. If onset can be delayed, the individual may die before developing clinical dementia (Mortimer, 1987; Katzman, 1993). Other studies supporting the 'use it or lose it' argument in dementia (Gall, 1992; Katzman, 1993) indicate that further research needs to be done in this area. If mental activity can reduce the risk or delay the development of dementia, this is a very important finding which has widespread clinical implications. Whether or not risk is reduced or development is delayed is a difficult question because of the theoretical arguments indicating that AD and ageing are a continuum (Brayne and Calloway, 1988).

However, until the 1970s ageing itself had little scientific status and had attracted little research from social scientists, and textbooks on social problems often included ageing along with alcoholism, delinquency, and mental illness (Beattie, 1984). This suggests not only that views of the ageing process may have changed little over the centuries, but also that the role of the social environment needs re-evaluation, particularly with reference to the mental disorders of old age such as dementia.

Perhaps, considering dementia, there is a parallel with how some psychiatrists view other psychiatric disorders as expounded by McClaren (1992). He points out that an exclusively 'organic' theory of psychiatry denies the possibility of psychological factors causing mental disorder. On the other hand a fully 'psychodynamic' theory would argue that the causes of mental disorder were purely psychosocial. Most contemporary psychiatrists would consider the effects of biological, psychological and

social factors in the possible aetiology, relapse, or deterioration of conditions such as schizophrenia and depression. Indeed, a considerable body of research has demonstrated that the human brain undergoes significant functional and anatomical changes in response to psychological influences (Gabbard, 1992). There are no compelling theoretical reasons why dementia per se should be regarded as a brain disease which is divorced from the mind and totally impervious to psychological and social stresses.

The development of the medical model of dementia has countered the longstanding assumption that senility is an inevitable consequence of old age. But the biomedicalisation of dementia has also been criticised on the basis that it leads to the demented person being viewed as a disease entity and a source of burden rather than an individual responsive to stress (Lyman, 1989).

Beattie (1984) raises the question of 'social' senility, suggesting that if people live long enough *'one could expect what could be called an increasing state of sensory deprivation'* as described by Butler and Lewis (1982) *'the experience of being cut off from normal stimuli and the opportunity for perceptions which occur experimentally or accidentally in various ways, such as in loss of hearing or eyesight, by being marooned, by solitary confinement... and which may lead to disorganised thinking, depression, panic, delusions, and hallucinations.'*

The work of Bowlby (1953) demonstrates the long term mental distress and maladjustment which can occur in infants placed in isolated environments. Even



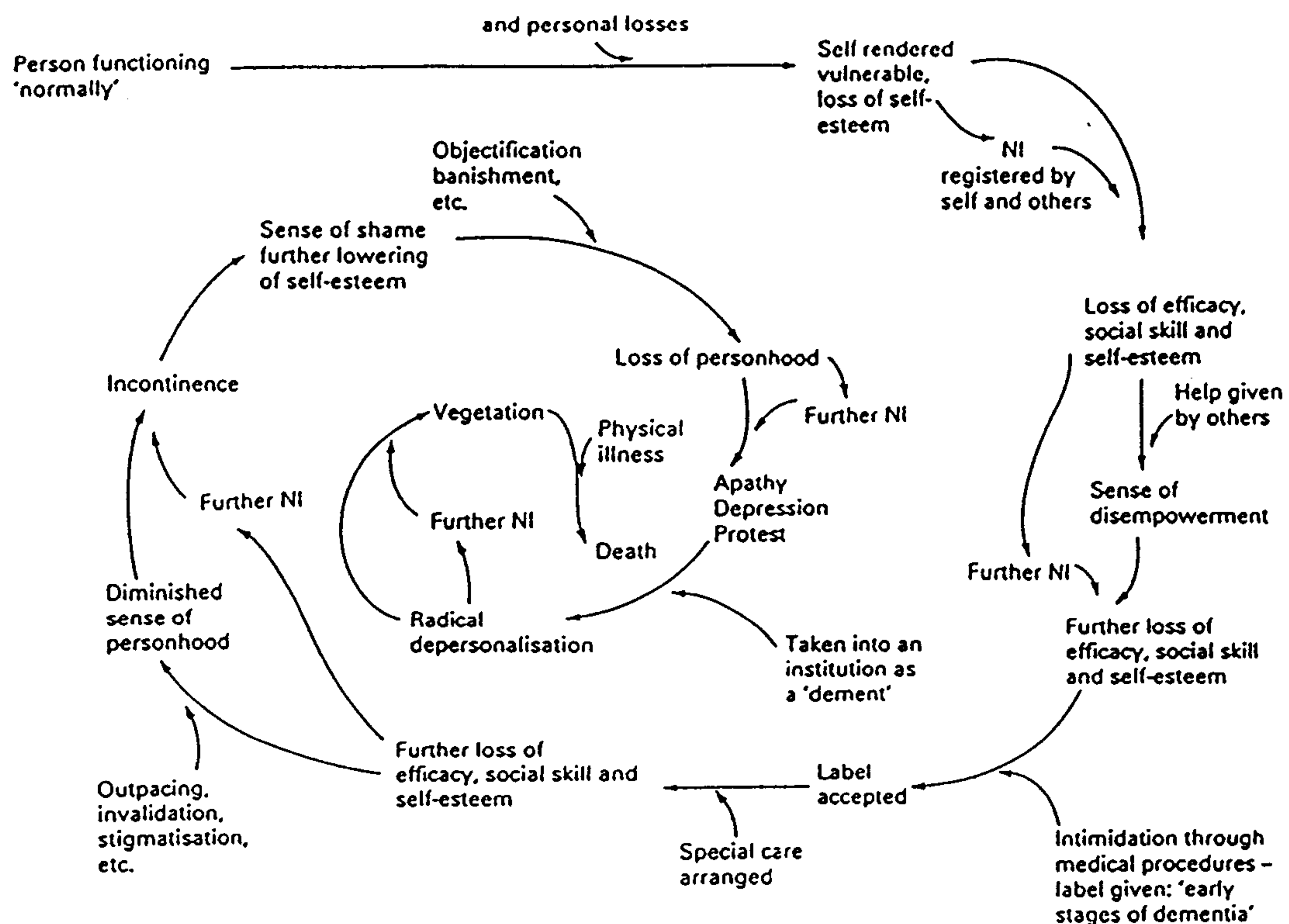
healthy adults subjected to sensory deprivation in experimental situations can develop a variety of mental symptoms such as hallucinations, difficulties in thinking, disorientation and confusion (Melin, 1976). Such is the mental trauma induced by sensory deprivation that it has been used in interrogation to reduce the subjects' resistance and willpower. It should be no surprise therefore that elderly people, with declining cognitive power or sensory impairments, or both, are vulnerable to sensory deprivation merely because they are not as receptive to the environmental stimulation of the world around them. Furthermore, when an individual develops dementia, his or her social field contracts, exacerbating any problems caused by insufficient social stimulation. Rosin et al., (1985) state that '*one of the most serious consequences of dementia is the isolation brought about by lack of social competence due to cognitive and personality deterioration*'.

The elderly also experience feelings of loss of mastery over self and environment as they become more highly dependent (Beattie, 1984). This is particularly so in the institutionalised elderly who may withdraw from communication and interaction partly because of sensory deprivation and partly because others have taken over their decisions (Beattie, 1984). Kitwood (1990; 1993) goes a step further than Beattie and attempts to produce a coherent model to take account of the interaction between psychosocial and neurological factors in the development and course of dementia in old age. In particular he stresses the importance of psychosocial factors which '*deprive a neurologically impaired individual of his or her personhood*' and questions the '*basic assumption of a straightforward linear relationship between neuropathology and*



*dementia*' which he says will not suffice for aetiological purposes since it does not give a full explanation of the process of dementia.

Kitwood suggests that *'subtle processes occur, which enable people to keep dementia sufferers at a psychological distance, and to avoid engaging them in their full capacity as persons'*. He attributes this to a general failure of our society to understand and provide for the needs and vulnerabilities of the elderly. Figure 1.30 is taken from Kitwood (1990) and shows his view of the potential influence of 'malignant social psychology' on the dementing process.



**Figure 1.3.0** The dementing process assuming some psychogenic causation of neurological impairment (from Kitwood, 1990)

Kitwood argues that the maintenance of self esteem is crucial to learning, efficacy and good social relationships, and that when self esteem is damaged by 'malignant social psychology' the individual falls into a cycle of discouragement and failure. The 'malignant social psychology' occurs when others treat the sufferer in a detrimental way, and for the individual with dementia this can be due to a number of social processes (Kitwood, 1990).

- |                  |                   |
|------------------|-------------------|
| ■ Labelling      | ■ Stigmatisation  |
| ■ Disempowerment | ■ Infantilisation |
| ■ Treachery      | ■ Intimidation    |
| ■ Outpacing      | ■ Banishment      |
| ■ Invalidation   | ■ Objectification |

Kitwood (1990) describes the malignant social processes with examples of how they might occur. For instance, 'treachery' occurs when some form of deception is used to get the dementia sufferer to comply with someone else's wishes, and 'outpacing' is when a carer continues conversation or activities too quickly and without sufficient regard for the dementia sufferer who is unable to follow what is going on. In 'labelling' the sufferer is treated differently because the diagnosis leads to expectations of decline or derangement and this may lead to 'stigmatisation', where the sufferer is treated as strange and tends to be avoided.

Incorporating the theoretical perspectives of Beattie and Kitwood it could be argued that cognitive and sensory deprivation plus malignant social psychology could have an

interactive effect on the individual with dementia, leading to distress, behavioural and cognitive deterioration, and so to increased dependence and incapacity.

### ***1.3.1 Effects of environment and routine change in senile dementia***

Patients with cognitive impairment (for instance, those with dementia or delirium) are often highly sensitive to their surroundings. It is well known that delirium often worsens at night when the patient's environment becomes less clearly defined. Indeed, part of the recommended management of delirium includes doing everything possible to make interpretation of the environment easy for the patient (Fairweather, 1991) including providing adequate lighting. Lipowski (1983) also describes a condition which he calls 'pseudodelirium', having similar clinical features but no clear organic causative factor, which occurs in up to 20% of elderly patients with symptoms and signs of delirium. He suggests that this condition may be induced by psychosocial stress, and this suggestion would be supported by the work of Beattie (1984) and Kitwood (1990;1993).

There are many ways in which dementia patients may be exposed to a psychosocial stressor involving a change in their routine or environment. Several of these will involve changes centred around the person's own residence, such as changes in the carer or structural modifications to the home. Also, changes may involve some form of move from accommodation, or loss or addition of some other regular and familiar activity such as attendance at a day centre. However, research in this field has focused on dementia sufferers who are resident in or attending some form of institutional provision such as hospital units or day care facilities.



The three principle types of situation investigated so far which involve degrees of environment and routine change are:

- Relocation
- Modification of an existing environment
- Specific therapeutic interventions

### ***1.3.2 Changes in environment and routine due to relocation***

A recent case-controlled prospective study looked at the effect on dementia sufferers of an enforced move (Anthony et al., 1987a) as a result of the closure of a large psychiatric hospital and the relocation of the patients to smaller units in two general hospitals. A large proportion of the sample showed significant depressive behaviour following transfer, and a significant degree of disturbed behaviour and disorientation remained three months after the move. This time lag suggests that the effects of relocation in terms of the stress, changes in routine, and changes in environment that accompany it, may be relatively long lasting.

Harwood and Ebrahim (1992) found no deterioration in cognitive function amongst 101 elderly continuing-care patients who were relocated from one hospital, which closed to refurbished accommodation at another hospital, and even noted a slight improvement in levels of dependency after the move. However, the patients were not necessarily suffering from senile dementia. Also, the results did not examine whether or not patients who were more cognitively impaired responded more poorly to the move, as would be expected since cognitive impairment limits the capacity to adapt to a changing environment. In the discussion, Harwood and Ebrahim note that another

study (Pruchno and Resch, 1988) found that those patients with moderate cognitive impairment and disability were most adversely affected by relocation, yet in their analysis they do not appear to have taken these findings into account. Both Anthony et al.'s and Harwood and Ebrahim's studies showed increases in mortality after relocation, but these were not statistically significant. However, an earlier study (Crank and Zweig, 1980) showed a significant increase in mortality amongst dementia patients after relocation following a hospital closure.

Considering the effects of relocation in terms of the degree of routine and environment change and the emotional stress associated with some sort of move, it is important to note that the studies carried out generally involve relocation to a more suitable and comfortable environment. In particular, the new accommodation was usually specifically refurbished with the needs of the frail elderly in mind, and offered better facilities with more single and double rooms provided. The hospitals which the patients came from tended to be old and in the process of closure (Anthony et al., 1987a; Harwood and Ebrahim, 1992). For these reasons the move might, in many ways, be seen as a positive rather than a negative event, and so be less stressful in the medium to long term, compared to a move with more adverse implications or conditions. With the latter type of move, it would not be unreasonable to suggest that, particularly for the elderly with dementia, a more obvious decline in function and an increase in disability and/or mortality would be observed.

The studies so far indicate that relocation for dementia sufferers may lead to depressive symptoms, disturbed behaviour and disorientation, which can persist for several



months. This is in spite of the relocation environment being designed for their needs and impairments.

### ***1.3.3 Modification of an existing environment***

The importance of having suitable environments for individuals with dementia to live in has been emphasised by the architect Michael Manser (1991). He notes that *'the clarity of design that helps normal people to understand buildings must be developed to an extremely sophisticated degree to make the building easier to use for demented patients'*. A recent study showed that even in the existing living environment relatively minor improvements can result in *'significantly improved psychosocial functioning in psychogeriatric patients'* (Minde et al., 1990). The majority of the patients were suffering from dementia, and a part of the study involved restructuring, refurbishing and decorating a day room in a far more homely style, together with a relaxation of the rules allowing patients to move furniture and have access to ward areas that were previously prohibited. Patients appeared calmer and interacted more, and the noise level was markedly reduced. Minde, although noting improvements, stresses the need for a more rigorous study to evaluate the changes. An earlier controlled study of changing the ward routine and environment for a group of dementia patients, Götestam and Melin (1981) found that both communication and eating behaviour of the study group improved. Stahler et al. (1984), also found patients' behaviour improved after the remodelling of a psychogeriatric ward to improve and rearrange the furniture and provide a better quality environment with colourful decor, reading material and orientation aids. A more recent study by Karlsson et al. (1988) indicated that environmental change may affect the concentrations of neurotransmitter metabolites in



the cerebrospinal fluid (CSF) in dementia patients. Patients in the study group were given increased environmental stimulation during their daily care and participated in group sessions twice a week. Both groups had psychological tests and CSF samples taken before and after the two month treatment period. Ratings of cognitive function, including concentration and recent memory, improved in the treatment group and deteriorated in the control group. CSF was tested for concentrations of HVA (homovanillic acid - the principle metabolite of dopamine), 5-HIAA (5-hydroxy indole acetic acid) and HMPG (4-hydroxy, 3-metoxyphenylglucol). CSF HVA concentrations increased in the treatment group (11 subjects) and decreased in the control group (13 subjects) ( $p < 0.05$ ) and this increase correlated with the improvement on psychological testing. A reduction in CSF HVA is known to be associated with dementia (Gottfries et al., 1970; Soininen et al., 1981). The authors suggest that *'environmental factors influence biochemical markers of transmitter activity which thus may possibly be of etiological importance in dementia'*. Although this study is important, in the current state of knowledge of the psychosocial aspects of dementia, the significance of the results is unclear because it was the first study of its kind and there were only small numbers in the groups. However, the results would seem to fit with the 'use it or lose it' hypothesis suggesting that positive mental activity had a beneficial effect. A replication is required, but this raises important ethical issues' since lumbar punctures involve risk without potential benefit to dementia patients.

#### ***1.3.4 Specific therapeutic interventions***

Thirty five years ago Cozin and his colleagues (1958), in a carefully observed project involving 'confused' elderly subjects, showed that regular occupational therapy and a

change in routine resulted in improvements in daily living skills such as eating and dressing behaviour and communication. Because the improvements were relatively short-lived after the programme ceased, the authors suggested that the main defect was that of motivation rather than cognition, since when the drive was provided by the therapist the performance improved. However, dementia sufferers have difficulty sequencing and organising activities because of memory difficulties; thus, they need guidance, encouragement, and restructuring of tasks. This is the more likely explanation for Cosin's results.

Over the last twenty years there has been a development of therapeutic techniques to try to help patients with dementia to cope with memory and orientation problems, to help them make the most of their remaining skills, and to help them to express and understand their feelings. The person with dementia can learn new information and show behavioural change with appropriate training (Morris, 1993) but at a slower rate and to a lesser extent in comparison to those without cognitive impairment. The three principle types of psychological techniques are:

- Reality orientation
- Reminiscence therapy
- Validation therapy

Of these three the only one which significantly effects routine and environment is Reality Orientation. Validation therapy (Feil, 1982; Bleathman and Morton, 1992) and Reminiscence therapy (Baines et al., 1987) involve work in small groups rather than changes to the individual's daily routine or modifications to the living environment.



For this reason Validation therapy and Reminiscence therapy will not be reviewed further. Reality Orientation (RO) was developed as a means of orientating elderly patients to their environment by continuous stimulation, in the hope that this will activate the neuronal pathways and so compensate for organic brain impairment (Morris, 1993). By its use of assisted focus, Reality Orientation (RO) can help to reduce the confusing elements in the environment, and has now been studied in depth (Holden and Woods, 1988). There are two main types of RO: 'classroom' and '24 hour' (which is sometimes combined with ward orientation training).

In 'classroom' RO three to five patients attend a group two or more times a week. In its simplest format this will focus on the date, weather and names of the participants, perhaps with discussion of topics which can be compared between past and present, such as food prices. Newspapers, photographs, or short film can be used to aid discussion. More advanced groups for less impaired patients may include cooking, shopping or outings (Morris, 1993).

'24 hour' RO involves two aspects. First, the restructuring of the environment to make it easier to follow using signs (e.g. toilet), clocks, calendars, pictures and an information board. Secondly, during communication, gently reminding the dementia sufferer of information such as their name, the date and time of day, where they are, and current events in their surroundings (such as an activity or a meal). Ward orientation training involves guiding the person around the ward, training them to use the environmental cues in order to help them get to any room or location they need.



Some of the early studies of RO showed benefits in the patient's verbal reorientation, self care and socialisation (Brook et al., 1975), whereas other studies did not, and Zepelin et al. (1981) actually found that the control group did better in terms of self care and social responsiveness. Considering the mixed results of these studies a review (Proctor-Powell and Miller, 1982) concluded that the benefits of RO were small and restricted in range; while it seemed to help verbal orientation, it did not change behaviour. Hanley (1984) has argued that the lack of efficacy in some studies may be because the RO has been ineffectively implemented. Holden and Woods (1988) also point out that RO needs to be carried out in a humane way and to maintain the patient's dignity, and should not appear mechanical or be like a cross-examination. The wrong approach can undermine patient's confidence and distress them by making them more aware of their failings.

Since then, the studies have been more positive about the benefits of RO, particularly when it has been combined with other techniques such as ward orientation (Reeve and Ivison, 1985) or reminiscence therapy. In a controlled study, Reeve and Ivison (1985) used a modified ward environment and 'classroom' reality orientation for dementia patients, and found an improvement in behaviour and cognitive function which was sustained at 12 weeks in the experimental group. Baines et al. (1987) in a controlled crossover study found that subjects who had four weeks of RO, followed four weeks later by four weeks of reminiscence therapy, showed improvements in cognitive function and behaviour problems as rated by the CAPE scales and an improvement in communication. RO should be a multifaceted, flexible approach, and may well be an effective technique when it is properly implemented. In particular, the attitudes of the

staff in applying RO are important and should be sensitive to the individual (Morris, 1993). A considerable number of studies have thus shown that dementia patients are sensitive to changes in their environment and routine. Preliminary work even suggests that environmental change can affect neurochemistry, which would have implications for our conceptual understanding of dementia. Therapies such as Reality Orientation which enrich the environment and daily activities of dementia sufferers appear to have some positive affects on cognition and behaviour.

In conclusion, positive changes in the routine and environment of dementia sufferers may be beneficial, whereas negative changes appear to be detrimental. In clinical practice, relatives often date the onset or deterioration of the condition to some particular event such as the death of a spouse. Although this is merely anecdotal evidence, it does suggest a fruitful line of enquiry because studies of other illnesses have been stimulated by similar observations.



#### ***1.4.0 History of life events research***

In everyday life, many of us may experience illness as a result of a stressful event, such as loss of a job or bereavement (Katschnig, 1986). The popular belief that stressful events can make someone not only unhappy, but also ill, has contributed to well known sayings such as 'a broken heart'. Disappointed ambition and unhappy love appear alongside syphilis and inherited tendency in Esquirol's 1827 book which features a table of the 'moral and psychological causes of insanity' (Cooper, 1986). Griesinger went on to develop an aetiological view of mental illness which allowed for a variety of factors contributing to the genesis of disorder (Cooper, 1986). The factors could be biological or psychosocial, and the relative importance of the individual factors, should therefore be assessed in each individual case. He stipulates that two criteria be satisfied in considering a factor causal. First, the event must precede the onset of the illness, and second, it must be linked with the illness either by demonstrable pathogenesis (e.g. head injury and brain damage, intoxication) or by a positive statistical association, or both. Research over the past thirty years has suggested that many illnesses, both physical and psychiatric, can be caused or influenced by adverse stressful experiences. Researchers have broken up the general category of stressful experiences into three groups: Daily hassles, which comprise the minor irritating and frustrating events of everyday life (such as arguments or traffic jams - Kanner et al., 1981); chronic difficulties (such as poverty or family problems - Brown and Harris, 1978); and life events (such as moving house, bereavement - Brown and Harris, 1978). Of these, life events have been studied in most depth and seem to be the most important stressor in terms of their capacity to precipitate illness.



Indeed, life events are now an essential consideration in the assessment of many psychiatric disorders.

#### ***1.4.1 Methodology of life events research***

Early studies looking at events requiring social adjustment (life events) concentrated on the number and types of events rather than the degree of change each life event carried. Realising the need for some estimate of magnitude, Holmes and Rahe (1967) developed the Social Readjustment Rating Scale in order to measure the severity of life events preceding an episode of illness. This comprised the use of a self-report questionnaire based on a fairly comprehensive list of 43 events which the subjects were asked to rate for the degree of 'readjustment' necessary, using marriage (given a fixed score of 50) as an anchor point. The life event deemed to require most readjustment by the respondents was 'death of a spouse' which achieved an average score of 100. In comparison to this, 'death of close friend' rated 37, 'change in residence' rated 20 and Christmas rated 12. This technique enabled the events to be quantified and paved the way for further research. However it did not give an indication of the degree of threat of an event and positive events could therefore sometimes score more than adverse ones. It has also been criticised because a cluster of several positive events can easily add up to produce a score of readjustment greater than a very major negative event such as death of a close family member (Brown and Harris, 1978).

There are many problems with using the checklist / self-report method of collecting life event data. As Dohrenwend et al. (1987) have noted, the great majority of studies

do not meet minimal criteria of methodological adequacy. This is primarily because checklist methods have often used inappropriate controls, do not take into account which events occur independently of the subject's prior mental state and behaviour, and have problems accurately dating events in relation to episodes of illness. As Creed (1993) has pointed out, such checklists often have ambiguous questions which leave the subject to judge what is a 'serious illness' or 'family member'. Since such questionnaires contain inherent ambiguity and make no attempt to prompt recall (or check the accuracy of replies), they may miss more than a third of life events (Klein and Rubovits, 1987), and can be very unreliable, with inter-informant reliabilities as low as 22% (Neugebauer, 1983). The poor recall for checklist methods is evidenced by the high 'fall off' rates for reported events from the date of interview. This may be as high as 5% per month for checklist methods but as low as 1% or less per month for interview methods such as the LEDS (and even lower for severe events) (Creed, 1993). Such a low 'fall off' rate is possible because interviewers take the trouble to prompt the person's memory using probes and reminders (Brown and Harris, 1978). Without such help fewer events are recalled and dating is inconsistent (Sobell et al., 1990). Without accurate recall and dating it is impossible to study life events prior to illness onset and overcome the bias of ill subjects, who may recall more negative events than a healthy group because of 'effort after meaning' (Creed, 1993). For example, depressed subjects may reflect on their recent or distant life experiences looking for reasons for the development of their illness. This may lead to a spuriously high rate of life events for the weeks prior to illness onset, suggesting a link between depression and life events when the results are actually due to recall bias. Studies using mood induction techniques in students can mirror this effect, with those in the



depressed mood state listing more negative events and fewer social supports (Cohen et al., 1988). Thus, for compelling reasons the simple checklist method is inadequate for serious life event studies.

Early controlled studies investigating a link between life events and the onset of depression often used medical inpatients as the control group. This raised questions about the validity of such a group as a useful comparison, since life events have been shown to be associated with the development of a number of physical illnesses. What was needed was an estimate of the average rate of life events in a comparable group of fit people. Paykel et al. (1969) avoided this stumbling block by comparing a group of 185 depressed patients with a healthy, randomly selected community group, matched individually for age, sex, marital status, race and social class. Paykel divided the events into 'entrances' (gains) and 'exits' (losses) from the social field. Only losses (exit events) were increased in the depressed patients. This suggested that only events involving a negative or threatening component (losses) were sufficiently stressful to precipitate a depressive illness. A study of the desirability of life events (Vinokur and Selzer, 1975) also found that only the number of *undesirable* events (rather than desirable events) correlated with the degree of emotional disturbances and behavioural indications of stress such as traffic accidents. These studies suggested that it was severe and adverse life events which were more likely to precipitate psychiatric disorder.

However, some events such as the break up of a relationship could well be precipitated as a result of an individual already developing a psychiatric illness. Although Paykel



recognised that some events may be a **consequence**, rather than the cause, of the illness, it was Brown and Birley (1968) who specifically incorporated this idea into the methodology by adding a rating scale for the degree of 'Independence' of each event. Their study (Brown and Birley, 1968; Birley and Brown, 1970) also used a community sample, but matched with a group of 50 patients admitted because of an acute onset of schizophrenia. Events were classified as 'Independent' if they were for all practical purposes outside the subject's control, and 'Possibly Independent' if there was no evidence that they had been precipitated by some aspect of the subject's behaviour but the possibility of such a link could not be excluded. These two types of events were found to be significantly more frequent in the patient's lives compared to the controls. They concluded that this was good evidence to suggest that environmental factors can precipitate an attack of schizophrenia, and that those events tend to cluster in the three weeks before onset.

Later work by Brown and Harris (1978) made a number of important advances. They developed a standardised semi-structured interview known as the Bedford College Life Events and Difficulties Schedule (LEDS). The LEDS is a sophisticated method for eliciting, recording, and accurately dating life events, and is widely considered to be the most valid and useful research instrument for that purpose (Creed , 1993). The reliability of Brown and Harris's contextual measure of threat is very good, even with previously inexperienced raters who have had only brief training (Tennant et al., 1979).

In addition, Brown and Harris (1978) established the use of an independent 'panel' for rating the level of 'threat' to the subject (without knowledge of the subject's emotional reaction to the life event) and the 'independence' of the event as elicited from the LEDS interview. In this way it is possible to avoid using the individual's own *subjective* estimate of threat or stressfulness which is likely to be biased by the subject's own mood and psychiatric state. The independent 'panel' method therefore enables an objective measure of threat to be made without bias either in reporting by subjects or in assessment by using the interviewers' views of the degree of threat which might be influenced by their perception of the subject. The 'panel' can also be 'blind' as to whether or not the subject is from the patient or control groups. This means that the 'panel' ratings will not be influenced by their own prejudice about whether life events are more common in a particular group of subjects. This is important as many studies have now shown increases in life events in patient groups compared to controls: the interviewer and raters are likely to know of this research.

As has been discussed, the semi-structured interview (preferably using the LEDS) is the best method for life events research because it is far more reliable than the checklist method, with a rate of agreement between patients and relatives of around 80% (Brown and Harris, 1978). In addition, it can reduce the problem of effort after meaning, reduce ambiguity, and date events accurately, it also has a low 'fall off' rate and can improve recall to acceptable levels. The LEDS includes a contextual measure of threat which means that the relative threat for that particular individual at a particular time can be rated. Lastly, the rating of the LEDS is by a trained,



independent 'panel' of raters who are blind to the diagnosis (if present) of the subject, which means ratings are made without this potential bias.

Although early research on life events focused on 'changefulness' (in terms of the degree of social readjustment needed) as a measure of the psychosocial stress experienced by an individual, this measure was later abandoned in favour of 'threat' because positive or desirable events seemed unrelated to the development of psychiatric or physical morbidity (Bebbington, 1987). However, these are not mutually exclusive dimensions; it is of course possible both to measure threat and to quantify changes in the subject's routine and environment associated with specific life events. This may be of particular importance in certain populations (such as dementia sufferers), where the individuals are especially sensitive to routine or environment changes. Rating changes in routine and environment would also allow evaluation of the theory that life events act by causing disruption of social rhythms (Ehlers et al., 1988). Measures of the changes in routine occasioned by a life event were originally developed by Brown and Harris (1978), who did not, however, take the measure further. More recently, Orrell et al. (1990) have shown that changes in the routine and environment brought about by a life event can be reliably rated after a brief period of training. The concept of threat as elaborated by Brown and Harris (1978) probably implies, at least sometimes, a degree of changefulness, along with several other attributes.

For the purpose of assessing life events in demented subjects, there are considerable advantages in deriving a power measure of change in environment and routine. In



order to understand better the way that life events act it is necessary for these new measures to be subjected to further research.

### **Life event research methodology in the elderly**

Relatively little is known about the effects of life events in the elderly because there has not been as much research in these age groups (Orrell and Davis, 1994). Much of the research has used the checklist approach, with its inherent drawbacks of poor reliability and lack of context, which means that the overall stressfulness for the individual cannot be properly assessed (Dohrenwend et al., 1987).

A study of more than 3000 people found that the younger ones tended to regard the elderly as more needy and disadvantaged than the elderly themselves did (Ferraro, 1992). This could cause problems for some methods of evaluating life events. A study of attributional style suggested that older people may be more likely than younger people to see bad life events as due to stable but specific factors. But older people who attributed outcomes to more internal and global factors also reported their health to be worse than that of others (Lachman, 1990). Since Lachman compared psychology college students to volunteers from senior citizens organisations these groups cannot be seen as representative of the old and young community populations. Volunteers are likely to be more motivated, and college students may be of higher intelligence on average than a representative group of adults of the same age.

In a study designed to assess whether age affects the reporting rate of life events, Oei and Zwart (1990) compared younger (< 45) and older (> 45) age groups. They found

that the younger group reported more life events than the older group, and depressed subjects reported more events than the non-depressed. However, their study suffered from a number of serious methodological problems which render the results difficult to interpret adequately. First, they used the checklist method (which they themselves note to be low in reliability) with the inherent problems of inaccuracy in terms of the 'threat' or 'undesirability' of an event. They even point out that most of the events listed "*do not unequivocally satisfy the criteria for 'exit', 'desirable' or 'undesirable'.*" In addition the two control groups were inappropriate. The instrument also had a bias towards increased reporting of events in younger age groups because it included employment-related questions. They concluded that *'the most prominent life events and depression researchers opt for the interview approach in preference to the self-report questionnaire'*. From the results it is impossible to ascertain whether younger age groups experience more life events or whether faulty methodology has given a spurious result. French et al., (1992) note the problem of the confounding of life event reporting with health status when life event checklist methods are used in the elderly. They suggest that *'health problems may lead to objective undesirable events or reduce the potential for objective desirable events'*. This could be more of a problem in the elderly because of the higher rate of physical illness but also highlights another difficulty of employing checklist methods.

Fortunately the reliability of the Brown and Harris's LEDS interview is equally good in an elderly population, even when used by previously inexperienced raters who have had only brief training (Wilkinson et al., 1986). Comparing 24 young adult subjects and 24 elderly subjects who rated the threat of 36 life events drawn from a community



study of elderly people, these authors found no significant differences in agreement between the two groups. In addition, the ratings of threat by both young and old subjects were in close agreement with the ratings of a trained panel, whether contextual detail was supplied or edited out (Davies et al., 1987). This is important since in studies of the elderly the researchers are generally younger; these findings therefore suggest that such age differences between the raters and subjects do not effect the overall reliability of the ratings. Since some elderly people may have memory or other cognitive difficulties, some studies have looked at life event rating by informants to assess the reliability of life events reporting. Informants' accounts of the life events of elderly subjects is in close agreement with the subject's own account, completely so for severe life events (Murphy, 1982).

#### ***1.4.2 Mechanisms of action of life events***

The effects of a life event on the individual depends on a number of factors:

- The degree of threat (Brown and Harris, 1978)
- A predisposing vulnerability to develop an illness (Brown and Harris, 1978)
- How the individual evaluates the meaning of the event (Brewin, 1990)
- Coping strategies of the individual (Brewin, 1990)
- Presence or absence of social support (Brewin, 1990)

Most critical life events require accommodative problem-solving and assimilative evaluation processes which operate on cognitive and emotional levels (Becker, 1986). These regulative activities may seriously over-strain the existing coping abilities and psychodynamic 'defences' of the individual, particularly if they have a degree of



vulnerability which predisposes them to a specific illness, or may result in them using maladaptive processes for coping with and adjusting to the effects of severe life stresses. In this way individuals may have a biological or psychological predisposition for adverse life events to cause excessive stress on their adaptive mechanisms, and this in turn can precipitate illness.

Considering the possible psychosocial mechanisms for the action of life events, most theories use depression as the model. However, life events appear to have a general stressor effect precipitating many physical and psychosocial disorders, not just depression. The arguments using the precipitation of depression as the model for the action of life events can, therefore, be justifiably extended to apply to the effects of life events in general. Brown and Harris (1978) suggest that the effects of life events are mediated by cognitive processes through the subject's self esteem. High self-esteem has a protective effect and low self-esteem an undermining effect on the subject's capacity to avoid depression when exposed to psychosocial stressors such as life events. This concept is employed by Oatley and Bolton (1985) in their social-cognitive theory of depression in reaction to life events. They suggest that life events act by disrupting roles by which people define their worth, particularly if they lack an alternative source of self-definition. Ehlers et al. (1988) seek to unify the social and biological arguments by suggesting that psychosocial stresses disrupt the individual's social rhythms or 'zeitgebers' which in turn could result in a disruption of the body's biological rhythms, causing depression.

In order to determine that life events cause psychiatric disorder, certain criteria should be fulfilled (Cooke, 1986; Maes et al., 1987):

- Clear statistical association between life events and psychiatric disorder
- Evidence that life events lead to illness, not vice versa
- A satisfactory theoretical explanation for life events specifically leading to disorder (taking into account the effect of possible confounding variables)
- An association between life events and illness replicable across different populations and times

### **Mechanisms of action of life events in the elderly**

Older adults might be expected to be at particular risk for the adverse effects of life events because of their increased frailty, decreased adaptability and vulnerability to physical and mental ill health. However, on the positive side, they may have coping skills born of experience with similar types of event in the past, so acquiring a degree of resilience (Orrell and Davies, 1994). In an interesting developmental perspective, Rook (1989) presents a 'social clock' model whereby events are more threatening if they are 'off time' for the life stage (e.g. death of an adult child of an elderly parent). The action of life events in the elderly may well be amplified by poor social support (Murphy, 1982; Fry, 1989; Russell & Cutrona, 1991), with deficient support producing a vulnerability to depression in the face of stressful life events. Krause (1987) suggests that social support buffers subjects against adverse reactions to life events (such as depression).

Krause (1987) has argued that feelings of positive self-worth are essential for the maintenance of self-esteem and that self-esteem is preserved by social support when an individual experiences life events. A later study by Krause (1991) suggests that desirable life events involving an expansion of family roles tend to reduce depressive symptoms in older adults. Unfortunately, Krause's studies used checklists rather than the LEDS.

In a small study, Lam et al. (1987) found that the depressed elderly reported more negative cognitions than non-depressed, suggesting that the patterns found in younger adults are equally characteristic of elderly samples. However, they also found that social adversity was not related to depressive symptoms in either clinical or community samples. In addition, cognitions were more negative in the depressed subjects regardless of adversity, suggesting that they were primarily a response to the clinical state of depression. They concluded that there was no reason to believe that negative cognitions in the elderly were due to greater change or adversity, and that they could well be responsive to cognitive therapy. This last suggestion has been supported by studies of cognitive therapy in the elderly which indicate that it can work well in major depression (Leung and Orrell, 1993). Davies (1993) found that adversity (life events and difficulties) was significantly related to the number of DSM-III-R symptoms, and log-linear analysis showed that social support exerted a directly protective effect against depression. In conclusion, social support, self-esteem and cognitions may all play a role in the mechanism of interaction between adverse life events and development of psychiatric disorders such as depression.



### ***1.4.3 Life events and psychiatric illness***

Many studies have indicated a connection between life events and the onset or relapse of psychiatric illnesses (Creed, 1993). A review of epidemiological studies by Cooke and Hole (1983) concluded that 32% of psychiatric cases can be attributed to stressful life events, and Brown and Harris (1989), found that in a prospective study in Islington, 37% of women who experienced particularly severe events became depressed.

Brown and Harris (1978), studying the risk factors associated with episodes of depression in South London women, found an increased frequency of severe life events in the months before an episode of depression. Indeed, since Paykel (1969), many other studies (e.g. Bebbington et al., 1981; Cooke, 1981) have established the link between the onset of depression and recent life events. There appears to be no difference between the frequency of occurrence of life events before episodes of 'endogenous' and 'neurotic' categories of depression (Dolan et al., 1985; Bebbington et al., 1988). Further analysis suggested that people of lower social class are much more vulnerable to developing depression when they experience adverse life stress (Bebbington et al., 1991). This may relate to attitudes, coping strategies, social support or access to resources. Recent research with working class women has suggested that positive events can initiate recovery from depression (Brown et al., 1992), and this may be through raising morale or feelings of self-efficacy.

Life events can also precipitate relapse of schizophrenia (Brown and Birley, 1968; Leff et al., 1983; Bebbington et al., 1993). Recent work continues to show that life events

are important across the spectrum of psychiatric disorders including mania (Kennedy et al., 1983), panic disorder (Roy-Byrne et al., 1986), agoraphobia (Last et al., 1984) and obsessive-compulsive disorder (McKeon et al., 1984).

### **Life events and psychiatric illness in the elderly**

There have been few studies looking at life events and psychiatric illness in the over 65s (Orrell and Davies, 1994). In a community study of 188 elderly people Linn et al. (1980) used a version of Rahe's Recent Life Changes Questionnaire to examine the relationship between depression and certain life events in the previous year. Although they found that depressed subjects were more likely to have experienced life events with a high degree of threat, the degree of distress engendered by the life event was based on the subject's own perception. Such a subjective measure obviously introduces a bias since depressed subjects are more likely to report distress about many aspects of their life. Patrick and Moore (1986) looked at life events and attributional styles as predictors of depression in elderly women by using the Geriatric Schedule of Recent Life Events (GRSE). They found that the undesirable life events which the subject felt helpless to control were significantly related to depression. They related this to Seligman's 'learned helplessness' model (Seligman, 1975). In addition to their use of a checklist they made no independent assessment of the controllability or independence of life events to minimise subject bias. However, their results may indicate the importance of the subject's own perception of the controllability of the life event.

Using the LEDS, Murphy (1982) compared 168 community controls selected from local general practices with 119 patients who had experienced an episode of depression



in the previous year. Her results suggested an association between severely threatening life events, major social difficulties, poor physical health and the onset of depression. The higher incidence of depression in working class subjects appeared to be related to their poorer physical health and greater social difficulties. Murphy suggested that lack of a confiding relationship was a 'vulnerability factor' which made people exposed to life events more susceptible to developing a depressive episode. However, Murphy did not analyse her data with multivariate techniques (such as loglinear analysis) to allow for the contributions of the different variables. The follow-up (Murphy, 1983) showed that severe life events in the succeeding year contributed to a poorer prognosis, but a confiding relationship did not appear as protective. The results of Murphy's follow-up (which found a relatively poor prognosis for depression), have been criticised because of the relatively infrequent use of ECT particularly for the patient subgroup with more biological and psychotic symptoms (Baldwin, 1991).

Several other studies using the LEDS have also found an increase in independent severe threatening life events among depressed subjects compared to controls (Lam et al., 1987; Burvill et al., 1991; Evans and Katona, 1993; Davies, 1993). This suggests that the elderly are more likely to develop depression if they suffer a severe adverse life event.

There do not appear to be studies using the LEDS covering other psychiatric disorders and life events in the elderly, and this is probably because there have been fewer life events studies in this age group.



#### ***1.4.4 Life events and physical illness***

Although the relationship between psychiatric illness and life events has been illustrated, as with senile dementia, certain physical or neuropsychiatric disorders may not conform easily to a purely psychosocial model for the actions of life events. This is because such disorders may have a definable pathological abnormality which implies a predominant biological causation. Nevertheless, many physical disorders appear to be associated with life events. Creed (1985) identifies some of the problems with this type of life event research and mentions three ways in which the relationship between stress and illness can be researched. The first relates to studying a population exposed to a specific stressor (such as bereavement), and the second looks at a population with a certain illness and relates recent life stress to the onset or course of the illness. The third type of methodology involves the use of an experimental stressor in a given population. The first two types of research methodology have already been described with respect to life events, but the third, although more rigorous, is also more elusive because it may be dangerous (and unethical) to try and precipitate physical illness in the subjects. This section will show how life events have been implicated in a range of endocrine, neoplastic and vascular disorders which have a defined pathology, and will note how the presence of specific pathology does not exclude a causative process involving psychosocial factors such as life events. Moreover, since senile dementia also has a definable pathology, it will be argued that life events cannot be ruled out as potential influences on its cause or course.

Psychosomatic symptoms are by definition related to psychological distress which in itself may be precipitated by life events as has been described earlier in this chapter.

For this reason it is not proposed to review the literature on life events relating to physical symptoms where there is not a defined diagnosis and which may be to some extent psychosomatic - for instance abdominal pain.

A review by Rowland (1977) noted that life events have been frequently linked with the decline in physical health or the subsequent death of the elderly, indicating that their effect is not solely psychological. Parkes et al. (1969) demonstrated that in the six months following bereavement in widowers over 55, mortality was raised by 40%, the commonest causes of death being complications of atherosclerosis, such as myocardial infarction. In a study of 91 men admitted to a coronary care unit following myocardial infarction, Connolly (1976), using the LEDS, found an increased number of independent, threatening life events in the preceding 12 weeks compared with a matched control group.

The endocrine system also appears to be sensitive to life events. Recent research using the LEDS compared newly-diagnosed diabetics with siblings or age/sex matched community controls (Robinson and Fuller, 1985). The diabetics had a higher rate of severe life events and severe difficulties preceding the onset of the diabetes. The authors suggest that severe life events and difficulties may be triggering factors in the onset of insulin-dependent diabetes. Also, in a study of 208 patients with newly diagnosed Graves' disease (diffuse toxic goitre) compared with matched community controls, the patient group had more life events in the 12 months preceding the diagnosis. The patient group also had higher scores for negative life events (Winsa et al., 1991). It should be said that this study has been criticised for its methodology



(Harris et al., 1992). Stressful life events may also be common before the primary pituitary type of Cushing's syndrome (Carroll et al., 1976).

Two studies of life events (using the LEDS) in women suffering from relapse of breast cancer found very differing results. Ramirez et al., (1989) found a significantly higher rate of severe life events since surgery in 50 recently relapsed cancer sufferers compared to 50 controls who were in remission from breast cancer. In a larger study Barraclough et al., (1992) found no difference in life events between women who had relapsed and those still in remission. Considering that the methods were similar in both studies but Barraclough et al. with 204 women had a larger sample, it is probably better to conclude that at present there is insufficient evidence to associate stressful life events with relapse of breast cancer. A particular concern is that 17% (42) of Barraclough et al.'s original sample were not included, and of these 34 had refused. The non-participants had less favourable prognostic features, and it is possible that some people refused to be interviewed because they felt under too much stress because of recent life events. Further research needs to be done to clarify whether there is any link between cancer and stressful life events.

Cohen et al. (1991) used the third type of methodology (as specified by Creed, 1985) exposing individuals to the cold virus (the experimental stressor) in order to investigate psychological stress and susceptibility to the common cold. After completing questionnaires assessing degrees of psychological stress (including major negative life events), 394 healthy subjects were given nasal drops containing one of five respiratory viruses and 26 controls were given saline nasal drops. The subjects were then



quarantined and monitored for the development of evidence of infection and symptoms. Clinical colds were defined as clinical symptoms together with the presence of an infection as verified by the isolation of the virus or an increase in the virus-specific antibody titre. The index of psychological stress was a combination of three stress scales (including one measuring recent negative major life events) which formed a single principal component suggesting that they measured a common underlying level of stress. The results showed that the rates both of respiratory infection ( $p < 0.005$ ) and of clinical colds ( $p < 0.02$ ) increased in line with increases in the degree of psychological stress. The results could not be accounted for by other variables, and were similar for each of the five viruses studied. This study suggests that major negative life events can predispose an individual to viral infection.

To look at possible interactions between life events, psychiatric disorder and physical illness, Murphy and Brown (1980) in a community study using the LEDS, compared 81 Walthamstow women with new physical symptoms with 162 fit Camberwell controls. They found that 29% of those women who had developed a physical disorder had a psychiatric disturbance which could be dated as starting on average 7 weeks before the physical disorder. It was therefore suggested that the effect of life events on physical illness is mediated by psychological distress rather than an independent relationship (Murphy and Brown, 1980). Even if this is the case the link between physical disorder and life events remains, albeit indirect. Life events are also associated with an increased likelihood of medical services being contacted in response to a physical problem (Krause, 1988; Siegel, 1990).

### ***1.4.5 Life events, neurological and neuropsychiatric disorders***

Although many studies linking life events with psychiatric or physical disorders have been described, it could be argued that senile dementia would not merit such an enquiry for a number of reasons:

- 1) It is an organic degenerative disorder and is therefore not significantly affected by psychosocial factors.
- 2) Changes in the social field of such patients are less important because such patients are relatively unresponsive to environmental stimuli.
- 3) Dementia patients do not experience the same sort of distress because of their global intellectual decline.

The first reason is clearly not supported by the wealth of research already described which links life events with the onset or progress of physical disorders characterised by definable pathology. This shows that life events cannot only have a psychosocial action but must also be able potentially to lead to a degenerative pathology through some sort of intermediary process which might involve the stress control system. In addition, research will be described in this section which suggests that life events can give rise to or influence the course of various syndromes which involve brain abnormalities.



The second reason has been shown to be false by the body of research already described showing how dementia sufferers are less adaptable and highly sensitive to changes in their routine and environment. Moreover, it seems to be particularly those changes which we would normally associate with a high degree of psychosocial stress (such as change in residence) which appear to be most stressful to dementia sufferers.

In addition, as has been discussed in previous chapters, dementia sufferers experience a range of moods and emotions (as do we all) indicating that they experience distress and are not by any means a mere repository of a certain type of pathological change. This means that the third reason cannot be supported by the available evidence.

In conclusion, all three reasons for assuming that dementia is not influenced by psychosocial factors are clearly unsustainable. It can therefore be argued on theoretical grounds that it is worthwhile to pursue an investigation looking at life events and senile dementia because; life events have been implicated in many other illnesses, dementia sufferers seem particularly sensitive to life change such as relocation or change in environment and routine; theoretical mechanisms as to how life events might affect dementia sufferers have been already discussed and will be elaborated further in the following sections.

These arguments will be further supported by the studies describing how life events have been implicated in various neurological and neuropsychiatric disorders.

## **Epilepsy**

A recent review (Betts, 1992) concluded that it is time for proper studies of the association between epilepsy and stress. Betts warns that an exclusive reliance on medication can lead to *'medical care becoming a futile exercise in counting pills and seizures and maintaining prohibitions'*. He points out that many epileptics will tell their doctor that emotional states and life stresses influence their seizure frequency, and there are many anecdotal reports of stress increasing the frequency of fits. In a study of 12 epileptics, seizure frequency was found to be related to life events and daily stresses (Temkin and Davis, 1987). However the number of subjects in their study was very small, and their methodology with respect to rating life events open to question: daily events were based on a self-reported checklist rather than a semi-structured interview, and no independent rating of threat was made. The results therefore rest on day-to-day stress/event levels rather than on more severe events with more long term ramifications. A more recent study suggested a possible link between major life events and seizure frequency (Webster and Mawer, 1989). Betts (1992) suggests that changes in brain arousal lead to changes in excitability, which may affect neuronal firing. This could influence seizure discharge, particularly if it affects neurons which surround an epileptic focus.

## **Head injury**

Lishman (1987) notes that recovery from head injury is associated with environmental factors and proper evaluation includes *'detailed exploration of the life situation antecedating as well as following the injury'*. In addition, threats to family or personal



security and occupational difficulties often assume crucial importance, suggesting that even in clearly organic brain disorders life events must be taken into account.

### **Brain haemorrhage**

Penrose (1972) studied life events in the three months preceding subarachnoid haemorrhage in patient groups with or without berry aneurysms. The group without berry aneurysms had a higher rate of life events and emotional difficulties in the three weeks before the brain haemorrhage. This suggests that life events may cause a rise in blood pressure sufficient to cause rupture of an intracerebral vessel even in people with no vascular abnormality.

### **Stroke**

In 1954 Ecker reported research suggesting that emotional stress and threatening events preceded stroke. However, it was not until recently that the first proper case control study using the LEDS was published (House et al., 1990). Comparing life events and difficulties in 113 stroke patients with a group of 109 age/sex matched controls, House et al. found that the stroke patients were significantly more likely to have experienced a severely threatening life event in the year before stroke onset. Recognised risk factors for stroke were equally loaded in patients with and without life events before onset. Although the authors did not look at the independence of an event, they did exclude from the analysis those stressors which could be construed as 'illness related'. In speculating about the mechanisms whereby life events precipitated stroke the authors noted that there was usually a lag period between the stressful experience and stroke. This suggests that the effects of the stressor might take time to act fully.

## **Multiple sclerosis**

For over a hundred years there have been reports of stressful life events precipitating attacks of multiple sclerosis (Moxon, 1873; Charcot, 1878). This century there have continued to be reports of a link, and it was earlier suggested from a psychoanalytic perspective that major life changes provoke intense resentment or anger which somehow demanded an excessive amount of muscular or mental strain and so precipitate neuronal overload giving clinical symptoms. Although in the 50s and 60s there were a number of studies looking at emotional stress precipitating attacks, there were numerous methodological difficulties which left the results open to a variety of interpretations. Grant et al. (1989) used the LEDS interview and compared 39 patients with multiple sclerosis (MS) with 40 'non-community controls'. Subjects were interviewed about events in the year preceding the onset of the disorder. Cases of MS were significantly more likely to have had one or more moderately severe life event in the six months before onset. Although this is interesting, there are some problems with the study. For instance, the control group may not be a valid comparison since they were drawn from another study. We also do not know about the rate of life events in the community population with MS. It is possible that MS patients have a higher rate of life events than the general population, but without a community survey we will not know. Dysregulation of the immune system is given as a possible explanation for life events causing precipitation of MS, (since there are immune abnormalities in MS) and this fits in with studies showing that life events can reduce immunity.



## **Mental handicap**

Senile dementia bears comparison with mental handicap since both disorders are chronic, irreversible and associated with global cognitive deficits. It is beyond dispute that mentally handicapped individuals can experience distress. Bicknell (1983) emphasises the importance of understanding this, and also stresses the impact life events can have on such a person. Stack et al. (1987) compared life events in 19 mentally handicapped patients and a control group admitted to the same ward on the same day. They found that the mentally handicapped group had a higher incidence of life changes related to interpersonal conflict whereas the controls had a higher rate of changes in 'personal health habits' such as eating, alcohol or drug use. This last finding is hardly surprising, especially since the handicap group were usually residents of group homes, but it serves to illustrate some of the deficiencies in the study. Events were elicited by checklist, severity was not assessed, and although an effort was made to rate change in environment, no method was used for rating threat or 'independence'. The control group was unsuitable since it could give no indication of the rate or type of life events among mentally handicapped in the community. Admission to hospital for psychiatric or other illness has frequently been found to be associated with an increase in recent life events. Lastly, even the diagnosis of some of the 'mentally handicapped' described in the study may be in doubt since seven (out of 19) were not diagnosed as such when they left hospital. Other studies on adults with learning difficulties have found that life events and minor hassles in the lives of people who occasionally become verbally or physically aggressive can lead to an increased risk of violence (Wynne, 1989). Looking at behaviour disorders in mentally handicapped referrals from the community using a modified version of Paykel's Schedule, life

events were often found to precede the appearance of behaviour disorders (Ghaziuddin, 1988), and in particular individuals experiencing a life event were more likely to have a less severe degree of mental handicap than people who had not had a life event before referral. Although in this study it was stated that care was taken to include only 'independent' events, it is not clear how this was done and whether it was a decision solely of the author. It seems that this did not conform to the general principles of being logically independent of the subject's ability to have precipitated the event, since events such as 'arguments' and 'attending a music party' were included. In their recent review on behavioural and psychiatric disorders in adults with learning difficulties, Holland and Murphy (1990), comparing research on life events and psychiatric illness, point out that

*'there is no reason to suppose that it is not applicable in this group. In fact, it seems likely that life changes may be more stressful and the additional presence of learning problems likely to have a more significant effect on family dynamics, thus increasing the risk of relapse'.*

Cognitively unimpaired people can draw on their memory and experience, use their ability to plan and make decisions based on predictions of possible outcome. It is but a small step to argue on the same basis that individuals with senile dementia are likely to be more sensitive to life events than those with intact cognitions who are better able to adapt to changing life situations. This further suggests there is a need for research of life events in those with senile dementia.



## **Senile dementia**

Throughout this section, the arguments against life events research in senile dementia have been comprehensively rejected: life events appear to influence the precipitation or exacerbation of a range of neuropsychiatric and neurological disorders associated with clear pathological changes in the brain; dementia patients experience distress; dementia patients are sensitive to changes in their routine or environment which often accompany a life event.

Where there is implicit pathological damage, authors have speculated that the life events may act through effects on immune mechanisms (Grant et., 1989), or through the neuro-endocrine response to stress (House et al., 1990). In contrast, where psychiatric symptoms (Ghaziuddin, 1988) or seizure frequency have changed, the authors tended to argue in favour of the psychosocial effects of stress. This shows that there has been an obvious inconsistency between how different authors use physiological or psychosocial theories to explain how life events cause illness. Nevertheless, life events appear to have a role in a variety of psychological and physical illnesses and there is no evidence that particular life events cause specific illnesses. The stress response must therefore be a general reaction to a wide variety of possible life stressors. As such it will involve psychological and biological changes. How a person reacts in terms of the development of symptoms or illness is likely to be related partly to the nature of the stressor but also to the characteristics and vulnerabilities of the individual under stress.

Reed et al., (1990) looked at life events in the carers of dementia sufferers and found that they did not appear to cause a general disruption of caregiving activities. Instead, the study suggested that the carer's appraisals of life events were influential in determining the burden of caregiving. Unfortunately, this study had small numbers and used checklist methods (rather than the LEDS) which means that its findings are potentially spurious.

There is some controversy about the value of life events research in dementia. Pitt (1993) states that there is little convincing evidence that stressful life events are significant factors in the genesis of dementia. However, there have been few studies of the relationship between life events and dementia, and none with adequate methodology. For this reason there is no convincing evidence either to support or oppose Pitt's statement. On the other hand, Mortimer (1987) argues that because of the association between stressful life events and immune deficits, future studies of life events and dementia are justified. In this introduction it is argued that there are compelling theoretical reasons for such a study.

In a study of 25 female elderly patients with dementia compared with 25 fit controls using the Geriatric Schedule of Recent Experience (GSRE), Amster and Krauss (1974) found in the dementia patients double the number of life crises in the previous five years. They were cautious in interpreting the results, pointing out that cognitive decline could have begun prior to the illness being noticed by relatives and friends. Because of this, early symptoms of the illness could have precipitated more life crises in the dementia group. In particular, the small size, lack of diagnostic evaluations of cases,



possibility of recall bias and confounding with stressful events associated with the disease, raises serious questions about the validity of their findings (Mortimer, 1987). As Gilhoolhy (1984) has pointed out, impairments in coping ability in the dementia patients could mean that they do not deal effectively with stressful events, which could then become more serious life events or lead to further life events because of failure to take the necessary action to cope with the initial stressor.

In a recent study of risk factors in Alzheimer's disease, life events were not found to be more common in the dementia patients (Niino et al., 1990). However, there were methodological flaws which render the results highly ambiguous. The authors used a checklist of 20 life events enquiring about a 10 year period prior to the development of dementia. This checklist was not a standardised measure and had not been tested for reliability, and it included items like 'living alone' which are not classified as life events in other research. The reliability of the checklist is likely to be very low (as in many other checklist studies). The recall fall off after one year or more is higher for each extra year using checklists. As the onset of dementia may have been several years before the assessment, many informants would have to recall life events occurring from 15 to 20 years previously. In addition, most of the dementia patients' informants were spouses, whereas the control patients' informants tended to be their children. It is possible that spouses and children tend to report different life events; this would be more of a risk in a non-standard checklist approach. This all means that the results lack validity and do not add anything of importance to the scientific argument.

In the EURODEM meta-analyses study of risk factors in Alzheimer's disease, Jorm et al. (1991) concluded that there was no evidence from case control studies to suggest that life events were a significant risk factor and that further research would be unlikely to be fruitful. However, the meta-analysis only looked at specific life events (death of spouse, death of child and divorce) rather than life events in general. Several of the papers cited by Jorm do not mention life events (Broe et al., 1990; Hofman et al., 1989) and the ones which do appear to use either their own version of a checklist (Amaducci et al., 1986) or arbitrary categories such as 'five or more grief-causing life events' (Chandra et al., 1987b). Amaducci et al., (1986) found two life events (past undesired pregnancy and loss of valuable objects) to be higher in the Alzheimer's group, but because of the dubious nature of the methodology and the fact that they were asking about specific events covering the lifespan before onset of illness, means that the results cannot be considered reliable. Chandra et al. found no differences, but used as a control group medical patients with other diseases, some of which have an association with life events anyway, e.g. coronary artery disease. Another flaw in the meta-analysis is that Jorm et al. (1991) included studies not mentioning life events but merely deducing 'death of spouse' and 'divorce' through marital status. In one of the cited studies (Broe et al., 1990) Jorm is an author but there is no mention of life events in the paper. This suggests that the studies did not collect consistent life events data and made no effort to look at life events overall but only noted life events which they had empirically decided to collect. It is clear that the methods of collecting life events information used in the studies comprising the meta-analysis are more primitive than those used in the first significant life events research (Holmes and Rahe, 1967).



The major findings of life events research in other conditions have only come with reliable methodology, particularly with the Brown and Harris (1978) LEDS interview. Jorm et al.'s conclusions are unreasonable since hypotheses about life events can only be properly tested using adequate methodology and so far such research has not been done. The use of meta-analysis, though seductive, is entirely misplaced since it can only substantiate valid conclusions where the data are sound. The poor quality of the data arises partly because of the flawed research methods used in collecting it, and partly because the data collected were inconsistent between studies. It is difficult not to think that the conclusions of the meta-analysis reflect the author's prejudices about dementia rather than a research consensus since they have drawn very strong conclusions from very weak statistical evidence. Even a methodological critique of Jorm et al.'s paper in the same issue concludes that no consistent findings emerge with respect to life events as a potential risk factor for Alzheimer's disease (Clayton, 1991).

In conclusion, the onset or relapse of many physical and psychiatric illnesses has been linked with antecedent life events. This includes disorders which have characteristic neuropathology in the brain, emphasising that the effects of life events are not restricted to 'functional' illnesses. As has been discussed, there are compelling reasons for studying life events with respect to deterioration in senile dementia. Possible reasons against such a study have been systematically refuted. The studies so far have been incomplete and methodologically inadequate for testing hypotheses about the effects of life events on individuals developing senile dementia.

### ***1.5.0 Psychobiological mechanisms for the effects of life events***

The concept of a stressful event causing or contributing to neurochemical and even pathological change may be alien to scientists biased towards keeping the notions of biological change and psychological change separate. However, in the discussion of life events so far it is evident that they have been implicated in the precipitation or progress of various physical and psychiatric disorders even where there is specific pathology. It follows that an explanation of these phenomena is required to incorporate both the concepts of psychological stress and a mechanism for biological change.

In this section, life events will be used as an example of a stressor which can elicit the neuroendocrine stress response. In addition, a potential explanation will be given for how a combination of stress and the ageing process on the functioning of the hypothalamic-pituitary-adrenal axis can lead to abnormal glucocorticoid homeostasis and neuronal death in the areas of the brain implicated in the memory dysfunction present in senile dementia. In this way it will be argued that stress is a potential factor in a pathway which can worsen or even precipitate senile dementia.

The possible mechanisms for the action of life events have been reviewed by Turpin and Lader (1986) who suggested four possible 'schemata' for their effects in psychiatric disorder. In the first, a specific and direct effect of life event stress acts on a brain system, implying a specific component of stress response leading to a specific impairment. In the second model, the specific effects of a stressor rely on an interaction between the brain system implicated in the stress response and a separate system involved in psychological dysfunction. In the third and fourth models, there is



a concept of a general stress response and an increase in arousal. For the third model, the underlying vulnerability is related to poor premorbid functioning which is exacerbated by acute adversity, whereas in the fourth model, acute adversity breaks down coping mechanisms that had previously compensated for poor premorbid functioning in the vulnerable individual. In principle, the three main arguments centre around whether or not life events can act directly psychologically to cause morbidity, whether they merely activate a biological predisposition to a specific illness, or whether both psychological and biological factors are involved in the mediation process (Bebbington, 1987). Figure 1.50A shows the role of life events in the stress-vulnerability model of psychiatric disorder (from Turpin and Lader, p 35).

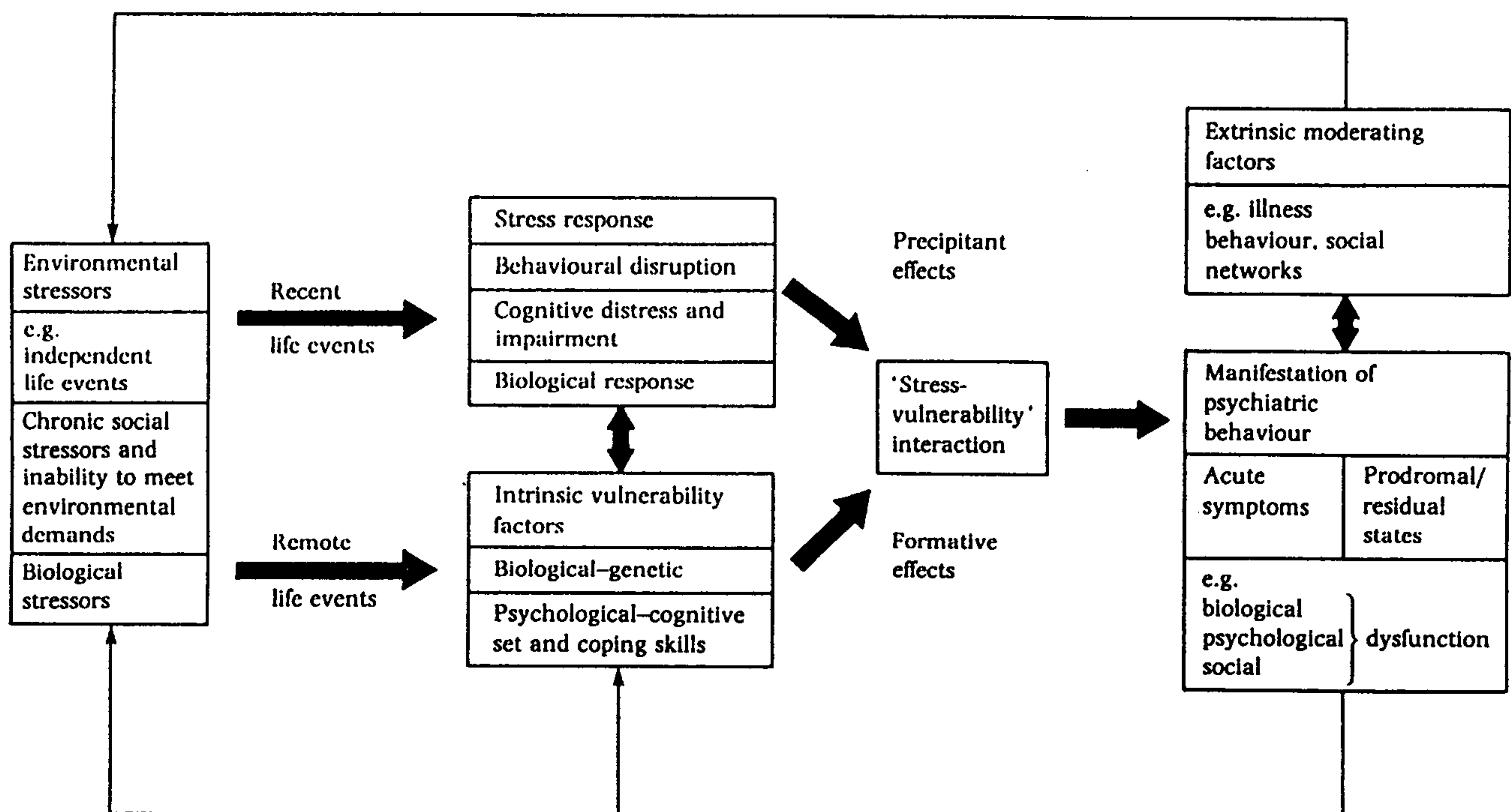


Figure 1.5.0A. The role of life events in the 'stress-vulnerability' models of psychiatric disorder

### **Life events, the hypothalamic-pituitary-adrenal axis, depression and dementia**

Severe psychological stress could lead to hormonal and neurochemical changes which might further impair compromised levels of function and might even, after a period of time, lead to some form of structural damage. For example, squirrel monkeys separated from their mothers experience elevated plasma cortisol levels. If these separations are repeated these physiological changes become permanent (Coe et al., 1978; Coe et al., 1983). Researchers interested in the precipitant effects of life events have tended to rely on monoamine theories of depression (Turpin and Lader, 1986). It is argued that changes in brain monoamines are associated with behavioural deficits in animals which are regarded as analogous to symptoms of affective disorders, and that uncontrollable adverse events may induce such changes. Checkley (1992) reviewed the possible neuroendocrine mechanisms involved in the precipitation of depression by life events. He concluded that life events could act by way of noradrenergic projections from the brainstem to the hypothalamo-pituitary axis and so the secretion of Corticotrophin Releasing Factor, ACTH, corticosteroids, and the actions of corticosteroids at type II corticosteroids receptors in the brain. Since life events are not associated only with depression, they must have a general rather than a specific stressor effect, and the neuroendocrine changes suggest possible mechanisms for their action should be applicable to the mechanism of action of life events in general. This theory has been supported by a study of initially healthy elderly people in which serum cortisol significantly increased after a stressful life event (Willis et al., 1987). In line with Checkley's model, animal studies show that increased corticosteroids bind to type II corticosteroid receptors in the limbic region of the brain including the noradrenergic and serotonergic projections to the forebrain. Corticosteroid receptors are intracellular

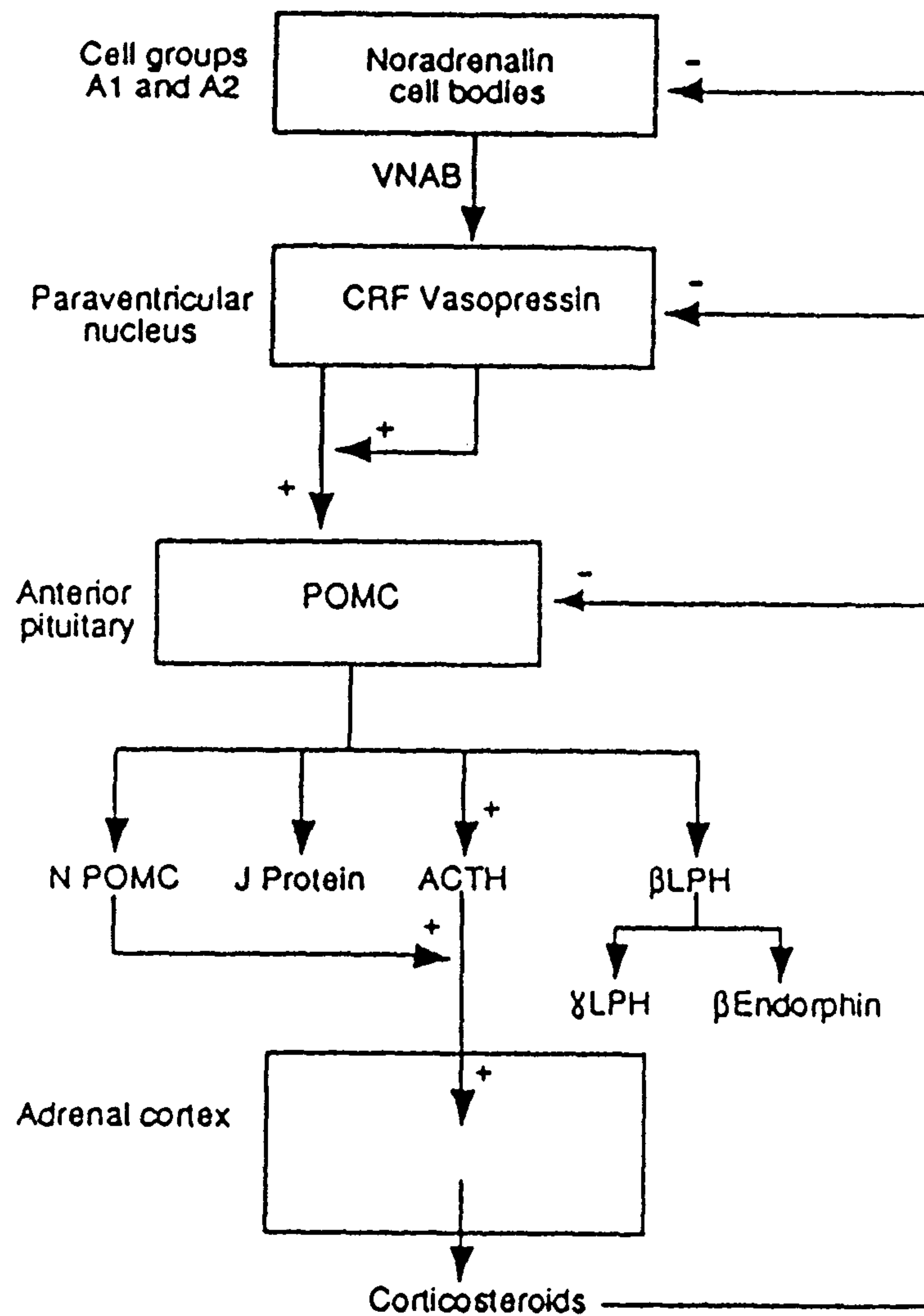


and, when bound to corticosteroids, are translocated into the cell nucleus where they bind to DNA and activate the transcription of M-RNA (Beato, 1989), suggesting a possible genomic link between genetic predisposition and the effects of life events (Bebbington and McGuffin, 1989) since corticosteroid levels could interact with a genetic propensity leading to psychiatric disturbance.

Checkley (1992) goes on to argue that the increased risk of depression in Cushing's disease may be related to the effects of high plasma cortisol and low plasma ACTH, particularly since lowering of the plasma cortisol and elevation of the ACTH reduces the severity of the depressive symptoms (Jeffcoate et al., 1979). This is supported by the finding that activation of the corticosteroid type II receptors is involved in the development of learned helplessness (Veldhuis et al., 1985). The hormones involved in the hypothalamic-pituitary-adrenal (HPA) axis are shown in Figure 1.50B (from Checkley, 1992).

The dexamethasone suppression test (DST) is used to test whether cortisol levels are responsive to suppression by dexamethasone (which mimics the action of ACTH). In an individual with normal negative feedback control (working through the HPA axis), dexamethasone suppresses cortisol output and so lowers plasma cortisol. Hypercortisolism is demonstrated by non-suppression after dexamethasone, and is found in 40-60% of depressed patients (Carroll et al., 1981). Although some researchers have suggested that it is a valid marker for 'endogenous' depression (Zimmerman et al., 1986), this hypothesis is doubtful because it is often abnormal in 'neurotic depression', schizophrenia (Powchik et al., 1987), dementia (Katona and

Aldridge, 1985; Alexopoulos and Abrams, 1991; Lawlor et al., 1992), other psychiatric conditions and in normal healthy controls (Sashidharan, 1984). In Alzheimer's disease 33% to 50% of non-depressed patients have DST non-suppression (Alexopoulos and Abrams, 1991).



**Figure 1.5.0B. Hormones involved in the hypothalamic-pituitary-adrenal axis in man.** VNAB = ventral noradrenergic bundle, CRF = corticotrophin releasing factor, POMC = pro-opiomelanocortin, N-POMC = N-pro-opiomelanocortin, β LPH = beta lipotropic hormone, δ LPH = δ lipotropic hormone.



As such, the DST appears to reflect a malfunction of the homeostatic mechanisms of the stress control response, implying that depression and Alzheimer's disease share abnormalities in the HPA axis (Alexopoulos and Abrams, 1991). This is interesting in the light of recent studies which suggest that a past history of depression may be a risk factor for the later development of Alzheimer's disease (Amaducci and Lippi, 1992). The HPA axis could therefore provide the theoretical foundation for a causal link.

The relationship between dementia, hypercortisolism and depressive symptoms remains unclear. Some studies have found more depressive symptoms in DST non-suppressors (Katona and Aldridge, 1985) whereas other studies have not found a link with depressive symptomatology (Lawlor et al., 1992) except for symptoms of agitation (which does not necessarily imply a depressive syndrome). There also appears to be no obvious relationship between severity of dementia and DST non-suppression (Katona and Aldridge, 1985; Lawlor et al., 1992). Roy et al. (1988) found a significant correlation between urinary-free cortisol and urinary outputs of norepinephrine and VMA (its metabolite) in depressed patients, but not in normal controls. They suggest that this finding consolidates previous work suggesting that dysregulation of both the hypothalamic-pituitary-adrenal axis and noradrenergic systems occur in depression.

The relationship between life events and hypercortisolism in depression has been explored in a number of studies. Three studies (Roy et al., 1986; Zimmerman et al., 1986; Roy, 1988) found a lower rate of undesirable life events in DST non-suppressors. However, only one of these studies looked at independent and non-

independent life events (Zimmerman et al., 1986), and only non-independent life events were fewer in the non-suppressors. This suggests that the excess of life events in the depressives with normal cortisol control might be accounted for by life events which they themselves had precipitated. Sashidharan et al. (1984), using the LEDS interview, found a higher rate of severely threatening life events in the depressives with DST non-suppression; however this study had only 14/37 patients who were non-suppressors, and the results did not reach statistical significance. In a study of life events using the LEDS with 72 depressed patients, Dolan et al. (1985) found that depressed patients who had experienced severe life events or difficulties had higher urinary free cortisols than the group of depressed patients who had not had life events. In contrast to the studies mentioned so far, Jacobs et al., (1984) looked at elderly subjects. They interviewed spouses of married persons between 45 and 80 who had recently been admitted to hospital because of a life threatening physical illness. In 53% of the cases the hospitalised spouse died within two months of admission. Jacobs et al. (1984) found that elderly persons under stress excreted more urinary-free cortisol than did a middle-aged group. When the results were stratified by depressive symptoms, the association between age and cortisol was accentuated for those with more severe depression, even when potentially confounding factors were controlled for. In a prospective study of initially healthy elderly people, Willis et al., (1987) found serum cortisol increased after stressful life events. However, this was a small study with a number of weaknesses, the authors have acknowledged the possible weaknesses and have been duly cautious in their conclusions.



Roy et al. (1986) also looked at hypercortisolism and CSF monoamine and monoamine metabolite levels in depressed patients. They found that patients who had not had a recent life event in the six months before the onset of depression had significantly lower levels of the dopamine metabolite HVA and the 5HT metabolite 5-HIAA than those who had a recent life event. It was concluded that the presence or absence of life events *'led to a separation into biologically distinct groups'*, but since independent life events were not looked at separately, it is possible that a higher propensity to initiate life events was all that differentiated the groups, and that the underlying rate of independent life events may have been no different. Decreased levels of CSF HVA and 5-HIAA are also found in Alzheimer's disease (Blennow et al., 1991), and the authors speculate that the findings reflect *'cerebral degeneration in Alzheimer's disease'*. This suggests that in some ways the CSF changes in dementia and depression are similar, again opening up the possibility of a theoretical link between the two disorders.

### **Life events and the immune system**

Stressful life events can also impair the function of the immune system (Irwin et al., 1987; Willis et al., 1987; Scheifer et al., 1983). Syvälahti (1987) reviewed the interaction between the endocrine and immune systems in stress, and concluded that there is much evidence to suggest that, in addition to autoregulation, the immune system is also *'under external regulation, especially by the endocrine and neural systems'* and that stressful life events can impair immune function and so increase an organism's vulnerability to disease states. Leonard (1990) states *'there is now a sufficient body of objective evidence to link stress-induced behavioural changes with immunological deficits and susceptibility to physical illness'*. Leonard (1990) argues

that the mechanism of mediation for the immune system is through the hypothalamo-pituitary axis, and this is likely since high cortisol levels can also suppress the immune system.

In summary, life events appear to be able to produce changes in hypothalamo-pituitary-adrenal axis function such as hypercortisolism, and can also impair immunity. Depression and dementia in the elderly appear to have similar neuroendocrine changes in terms of CSF monoamine metabolites and hypercortisolism. This suggests that psychosocial stressors and biological systems must be closely linked, and also provides the beginnings of theoretical explanations for the results of studies which indicate that life events can precipitate physical illness. In this way, life stress could lead to psychological change giving rise to depressive symptoms or neuroendocrine changes which in turn could worsen existing dementia or trigger the initial process of dementia. If this chain of events can occur, there are likely to be a variety of mediating factors, which may either modulate the effect of life events or be additional risk factors for the development or progress of the dementing process. Another question would however follow: Why is dementia so much more common in the elderly considering that overall they do not appear to experience more stress than other age groups? One possible answer to this question may relate to the effects of ageing on the HPA axis. This will be discussed in the following section.



### ***1.5.1 Aging, dementia and the hypothalamic-pituitary-adrenal axis***

So far, the links between life events and physical and psychiatric illness have been discussed in the context of abnormalities of the HPA axis that life events may induce. However, in order to provide a more specific theoretical pathway between life events and dementia it is necessary to examine the changes in the responsivity of the HPA axis with aging and the effects of corticosteroids on the aging hippocampus.

In Alzheimer's disease, and vascular dementia, memory deficits are characteristic clinical symptoms that occur early in the disease process (Wilcock and Jacoby, 1991). The hippocampus is a key area for memory storage and processing, and is one of the principle areas affected by the pathological changes of Alzheimer's disease (Esiri, 1991). The hippocampus is also a principle component of the HPA axis (Sapolsky et al., 1986). As part of the limbic system, the hippocampus has a role in how psychological stressors affect function of the HPA axis and control of the 'stress' hormones (Pert et al., 1989). The secretion of glucocorticoids by the adrenal cortex in response to a variety of stressors is the final stage in a neuroendocrine cascade which begins with the perception of a stressor by the brain and the triggering of hypothalamic release of Corticotrophin Releasing Factor (CRF). This stimulates the release of ACTH from the pituitary which in turn stimulates glucocorticoid release from the adrenal gland. Glucocorticoids act on receptors in the brain and pituitary to regulate the axis by inhibiting CRF and ACTH release. In this way, the axis forms a closed loop feedback system (Sapolsky et al., 1986). The hippocampus is distinguished from most potential glucocorticoid feedback sites because it contains both type I and type II corticosteroid receptors (Sapolsky et al., 1986). This allows the hippocampus to

regulate the HPA axis through a wide range of corticosteroid concentrations. Principally, the hippocampus inhibits basal cortisol secretion and helps to terminate the adrenocortical stress response (Sapolsky and Plotsky, 1990). Glucocorticoid hypersecretion can be caused by lesions of the hippocampus (Jacobson and Sapolsky, 1991) or by progressive loss of hippocampal neurons as a result of chronic exposure to neurotoxic agents such as alcohol (Pohorecky, 1981), which impair the functioning of the HPA axis.

In their theory '*The Glucocorticoid Cascade Hypothesis*' Sapolsky et al. (1986) discuss how hypercortisolism in the aging individual may cause hippocampal neuron receptor loss and neuron death and so lead to a dementing process. Rat basal glucocorticoid concentrations tend to rise with age (Sapolsky, 1991), the aged pituitary shows a dampened response to CRF, and the aged adrenal has a reduced response to ACTH (Hylka et al., 1984). Although the aged rat may be able to initiate stress responses appropriately, it is dramatically impaired in its ability to terminate it (Sapolsky et al., 1983). This causes corticosteroid hypersecretion, which leads to corticosteroid receptor loss, and damage and destruction of hippocampal neurons (Sapolsky et al., 1985; Sapolsky, 1985). The progressive hippocampal degeneration with age is worsened by adrenal hypersecretion (Sapolsky and Plotsky, 1990). Adrenalectomy can help reduce such neuronal damage (Sapolsky et al., 1985). Receptor loss leads to a decrease in the ability of the system to inhibit further corticosteroid release, resulting in a 'feed-forward' cascade which can lead to further hypercortisolism and potentially serious pathophysiological consequences. Prolonged glucocorticoid exposure can also cause hippocampal damage in primates (Sapolsky et al., 1990); it has been postulated that



conditions associated with chronic corticosteroid elevation such as Cushing's disease in humans may damage the human hippocampus. A recent study (Axelson et al., 1993) suggests that in depression hypercortisolism is linked with decreased hippocampal volume.

Memory impairment in aged rats correlates with hippocampal neurone loss and increased adrenal activity (Issa et al., 1990). Animals adrenalised in mid-life, in addition to showing decreased neuron loss have improved cognitive functioning compared to controls (Sapolsky et al., 1985). A recent study by Dodt et al. (1991), comparing young and elderly fit controls with Alzheimer's patients, found no difference in basal cortisol levels between the three groups. Both elderly groups had higher basal ACTH levels compared to the young controls. However, after administration of CRF/lysine vasopressin, the peak ACTH and cortisol levels were similar in the young controls and Alzheimer's patients but higher in the fit elderly. Moreover, in the dementia patients, the post-stimulus decline in ACTH levels was delayed. The results suggested an enhanced reactivity of the feedback mechanisms of the HPA axis in the mentally fit elderly, probably due to diminished sensitivity to negative feedback via glucocorticoids. This reactivity was attenuated in Alzheimer's disease (AD) patients, indicating alterations in the HPA axis. Dodt et al., (1991) point out that there is only sparse data about the function of the HPA axis in AD. They suggest that since studies have observed CRF depletion in the cerebral cortex of AD patients (De Souza et al., 1986) and acetylcholine may be involved in CRF regulation, the loss of cholinergic neurons (in the hippocampus) as occurs in AD may be a

mechanism whereby HPA function is disturbed. The abnormal DST results in around 50% of AD patients are also an indication of HPA axis dysfunction.

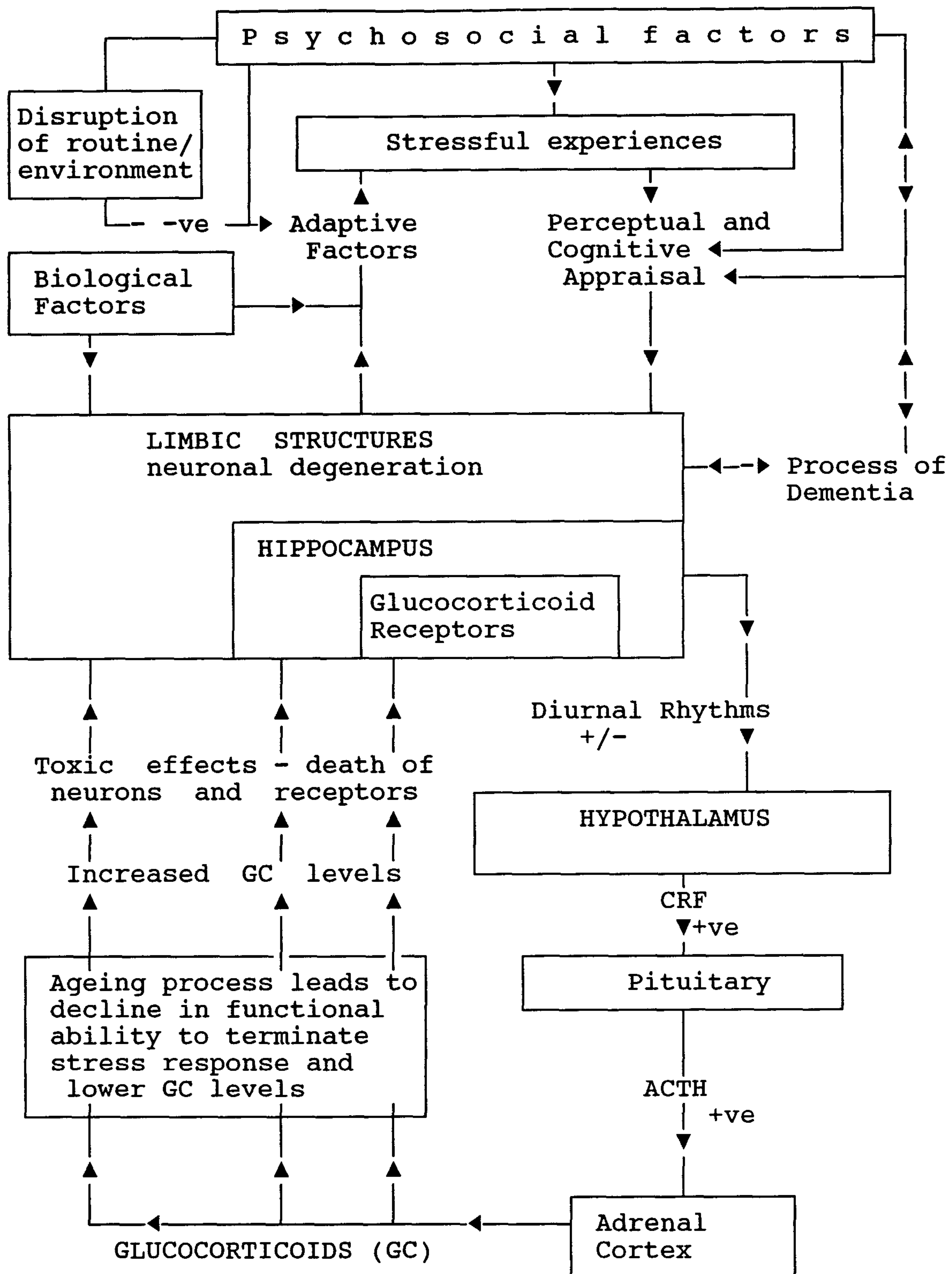
Although stress is a potential aetiological factor in the HPA axis dysfunction found in depression, there have been no comparable studies looking at stress in AD. There are fewer grounds, at least at the moment, for claiming that (1) stress leads to hypercortisolism which leads to dementia, rather than that (2) dementia leads to hypercortisolism. However, rat and primate studies suggest the first argument is correct, mediated by the toxic and lethal effect of high glucocorticoid levels on receptors and hippocampal neurons. However, there are few studies on humans which can address these arguments. Patients with hypercortisolism due to Cushing's disease also often show a range of cognitive impairments (Whelan et al., 1980) and cerebral atrophy (Momose et al., 1971), although this may be reversible with treatment (Lishman, 1987). This suggests that hypercortisolism in humans may damage neuronal function. Torture victims have also been reported to have a high incidence of cerebral atrophy, ventricular enlargement and dementia (Thygesen et al., 1970; Jensen et al., 1982). A severe stress like torture can lead to HPA axis changes and this could explain the dementia and cerebral changes. However, torture victims may also be subject to starvation and chronic malnutrition, which can also lead to cerebral atrophy. In dementia sufferers cognitive impairment on psychological testing has been found to be correlate with abnormal DST results (Karlsson et al., 1988).

To summarise, life stress can lead to depression, and this may be associated with hypercortisolism and disturbance of the HPA axis. There appears to be a similar



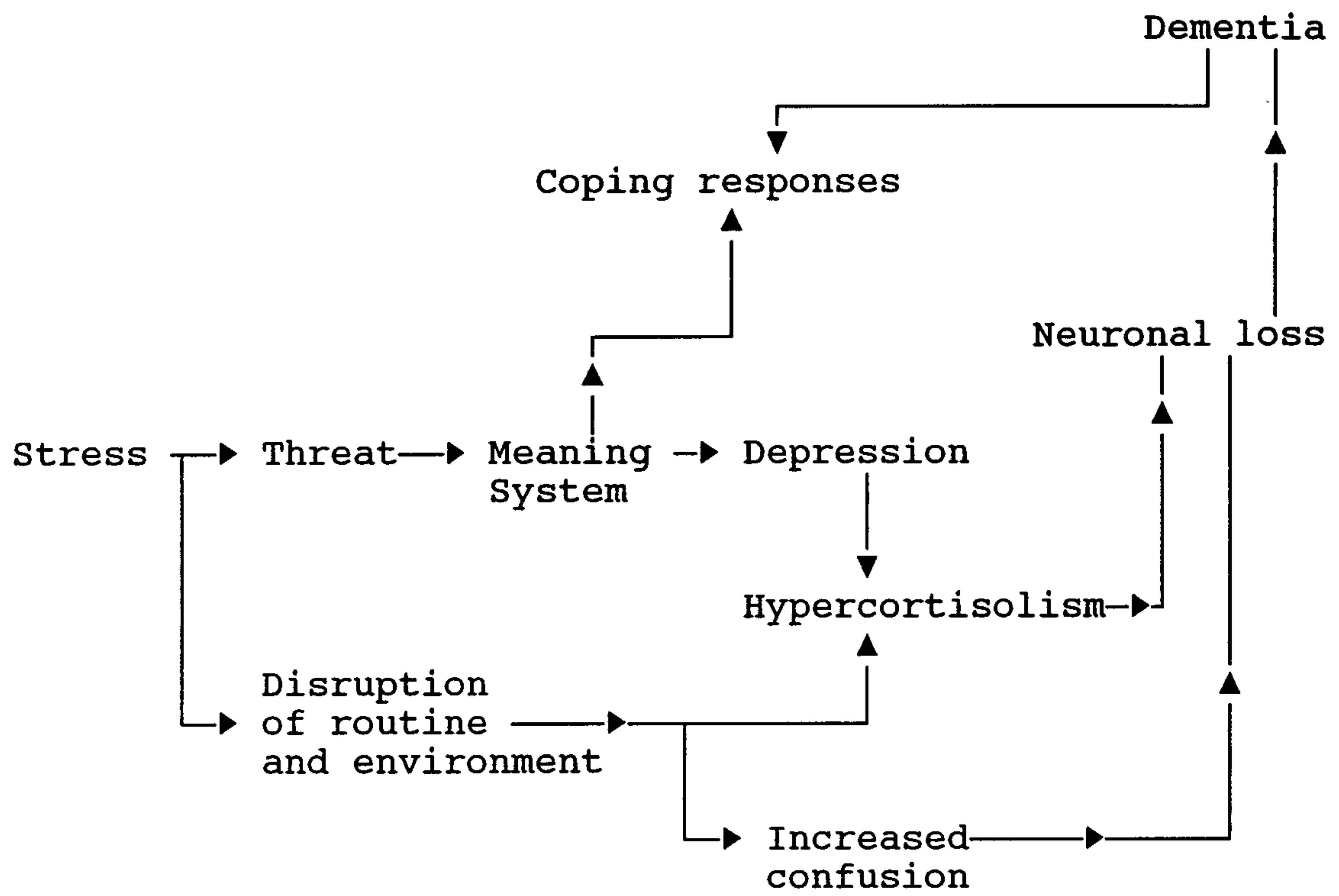
disturbance of HPA axis function in Alzheimer's disease characterised by hypercortisolism; this in turn may be associated with deterioration in related cholinergic or noradrenergic systems. This may be the link whereby stressful life events could potentially worsen neuronal loss. Such a link would also begin to provide and explanation for the finding that past history of depression appears to a risk factor for Alzheimer's disease (Jorm et al., 1991; Amaducci and Lippi, 1992). In addition, because of cognitive impairment, senile dementia patients may be less able to cope and adapt psychologically to life change. Lack of adaptation could potentiate the stressful effects, and in so doing prolong the neuroendocrine response to stress, resulting in hypercortisolism and further neuronal damage. All in all, there is now sufficient evidence at least to speculate that life stresses, through their effect on the HPA axis, may be involved in the genesis and process of deterioration in dementia (O'Dwyer and Orrell, 1994). Figure 1.5.1A shows a schematic representation of how this may occur according to the glucocorticoid cascade hypothesis.

Figure 1.5.1B takes the model the further to look at how depression might be incorporated. This model would predict a particularly high level of morbidity between depression and dementia which has indeed been the finding of many studies (Alexopoulos and Abrams, 1991).



**Figure 1.5.1A Possible mechanisms for stress contributing to the genesis or deterioration of dementia**





**Figure 1.5.1B Potential mechanisms linking, stress, dementia and depression**

### ***1.5.2 A biopsychosocial model for dementia, the theoretical role of life events and the precipitation of acute deterioration***

In a review of the conceptual history of dementia, Berrios (1987) stresses that the difficulties in diagnosis may be a result of the narrowness of the cognitive model of the disorder, which still 'reigns supreme'. He describes how at the end of the 19th century a similar situation existed, as attempts by the neuropathologists such as Alzheimer, Meynert and Pick to establish detailed clinico-anatomical correlations led to a demand for a stable clinical definition of the disorder. The clinicians responded by endorsing a cognitive view of dementia, which relied heavily on the assessment of memory functions and left out the affective and perceptual symptomatology. As has been discussed, cognitive function does not correlate particularly well with neuropathological indices (such as amyloid deposition) (Mullan, 1993) and may not adequately reflect the diversity of the dementing process when so many other symptoms are often involved (Förstl et al., 1993). In the first part of the introduction it was shown that current aetiological models could not explain the majority of cases of senile dementia. Likewise, simple cognitive or pathological models of the dementing process do not provide an explanation for the acute episodes of deterioration seen in senile dementia patients. Verwoedt (1976) suggests that severe psychological upsets can cause brain decompensation and that a *'progressive accumulation of disturbing emotions ..... may produce a neuronal turmoil which reduces the homeostatic and information processing capacity of the brain. When the status of the brain is already borderline, any further decrease of its efficiency is enough to tip the brain into decompensation'*. Recognising that brain impairment is the obligatory factor in patients suffering from dementia, Shan Wang (1977) notes in his authoritative review that



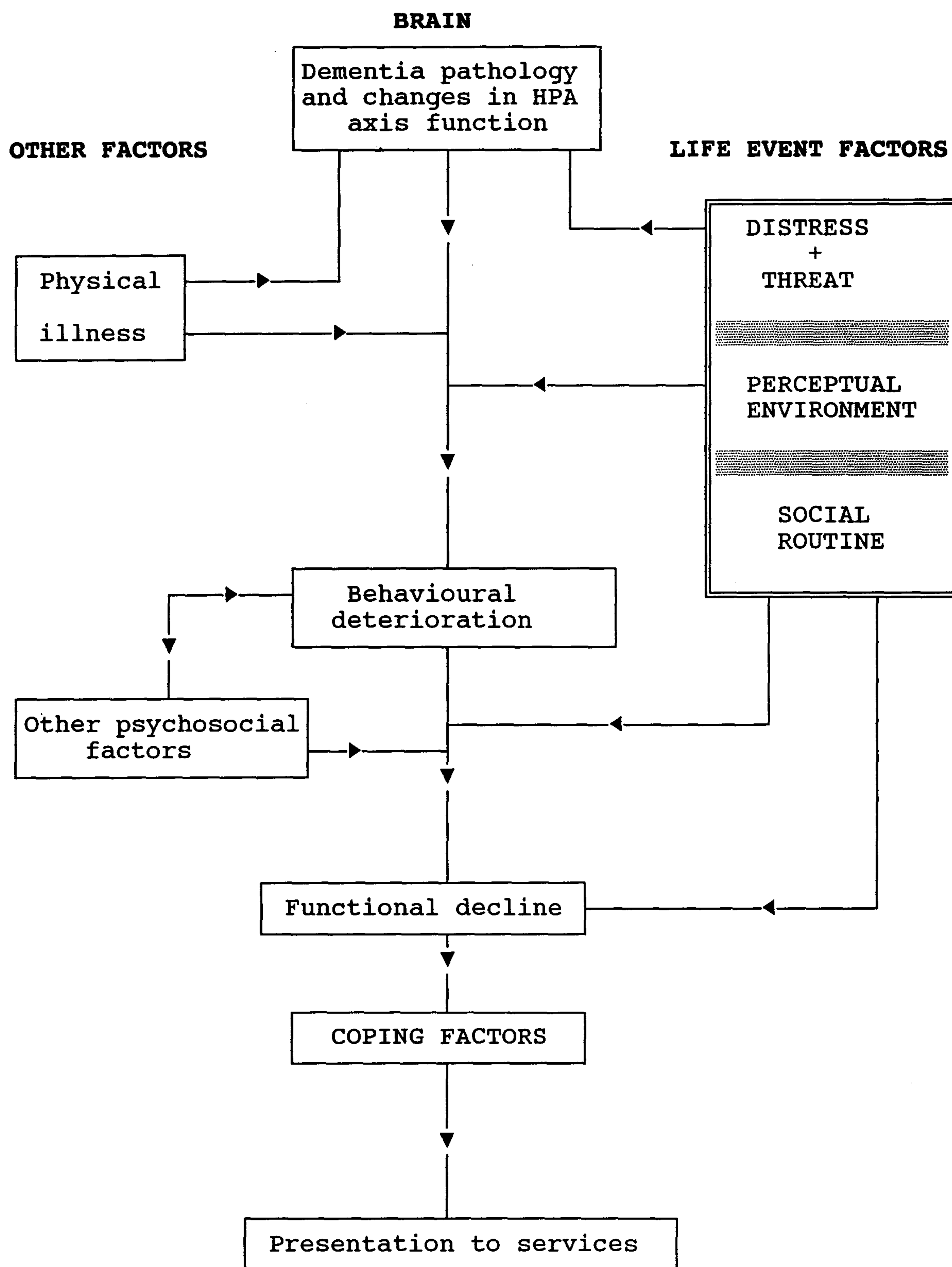
many sociopsychological factors play an important role in the course of the illness. These factors may aggravate behavioural manifestations of intellectual decline and undermine physical health. The interaction between these factors may in turn lead to further decline. Shan Wang proposes a 'Sociopsychosomatic' model for dementia which respects the part played by somatic, psychological and social factors, and proposes that since little can be done about brain tissue which has lost its functional capacity, the interplay between these factors often becomes the most important determinant of course and outcome. Since, even now, sixteen years later, we have no effective drug treatment for senile dementia (Byrne and Arie, 1990; Perry and Perry, 1993) and since we now appreciate in more detail the various psychosocial influences, it would seem that Shan Wang's model deserves serious consideration. This has been supported by recent theoretical and clinical research on psychosocial factors which appear to provide an alternative explanation for deterioration, and possibly onset, in senile dementia. In particular, dementia sufferers are sensitive to changes in their environment or routine brought about either by events such as relocation or by the various therapeutic strategies.

Life events have been implicated in the onset or recurrence of a variety of psychiatric disorders. However, their effect does not appear to be solely psychological since they have also been linked with the onset of physical disorders with definable pathology, and even with death. More specifically, certain disorders with identifiable brain pathology also seem to be precipitated or worsened by life events, again suggesting that identifiable pathology does not exclude psychosocial factors from the disease process.

Models of how the neuroendocrine system may be involved in the interaction between life events and the disease process have been discussed. It has also been argued that life events can cause disturbance in the hypothalamo-pituitary axis and through this have some sort of role in the dementing process. This might be through decreased immunity, or the genomic effects or the neurotoxic action of corticosteroids. In particular, recent work indicates that stress, aging, and the hypothalamic-pituitary-adrenal axis may all be linked to the development of dementing process.

In conclusion, the current clinical, pathological and aetiological models of senile dementia do not provide an adequate explanation for the wide variations in the course of the disorder between individuals, or even the acute episodes of deterioration which frequently precipitate hospital admission. Acute episodes of cognitive and behavioural deterioration may well be mediated by a combination of biological, psychological and social factors as shown in Figure 1.5.2A.





**Figure 1.5.2A Theoretical mechanisms for the process of life events contributing to causation or acute deterioration in senile dementia**

Life events were chosen for investigation as perhaps the most obvious example of a specific psychosocial factor which had already been established as important in many other illnesses, and could be elicited and quantified accurately using well-established methodology and instruments. The major impact of the life event has been generally considered to be due to the level of **threat** associated with it (Brown and Harris, 1978). The concept of threat is intimately bound up with the system of meaning. The major mechanism whereby the life event represented stress to the individual was thus through the **meaning** that it had for the person. The processes of evaluating the meaning of the event led either to adaptation and termination of the stress response, or to maladaptive processing and a persistent stress response leading to disorder or disease. As a result of the dominance of the **meaning** paradigm, previous studies looking at physical and psychological disorders and life events rarely examined changes in the social routine and environment as distinct dimensions. The emphasis on meaning results in some events bringing a considerable change in terms of routine and environment being rated as low on threat. Because of this it has not been possible to distinguish whether or not life events act primarily through the degree of threat or distress they engender or through a disruption of social rhythms (Ehlers et al., 1988). It is particularly important to be able to separate these dimensions in dementia patients, since they may be more sensitive to even minor disruptions in their environment and social routine. For this reason life events which are socially disruptive but have low threat may provoke deterioration in senile dementia patients because of their limited capacity to adapt to or understand a changing social environment. Paradoxically, life events with a high level of threat (such as death of a close relative who lives far away), may cause less deterioration because the patient's social environment has not been disrupted and their ability to perceive loss may have declined. However, it is also possible to argue the contrary, that life events can cause major



emotional changes (such as grief reactions as a result of loss) which may be more difficult to cope with or resolve for someone with senile dementia because their cognitive impairment impairs their ability to adapt to stress. Mood disturbance, particularly with agitation and anxiety, could in turn impair performance and exacerbate confusion, or could draw attention to someone with an existing dementia. In addition, impaired ability to adapt to threatening life events may help provide an explanation for the high rate of depressive symptoms in dementia. According to the arguments presented so far in this section the effects of a life event on a person with senile dementia may result either from the degree of threat or from the change in social environment that the life event brings (although it may be a combination of the two). This means that the level of threat and the change in social routine and environment need to be looked at independently. The current study does this.

This study examines life events before a dated acute deterioration and before admission in senile dementia sufferers admitted as day patients or inpatients to an acute psychiatric unit for the elderly. Admission is one index of deterioration (as are some of the other measures used in the study), but not everybody who has deteriorated in the community will end up being admitted or even necessarily being assessed by a doctor. It may well be that the family or other current help or services the patient gets can increase their support and continue to cope. Equally, even if the patient is assessed by the general practitioner, the general practitioner may or may not request a psychiatric assessment, and the psychiatrist may or may not advise on an admission. Even if the psychiatrist recommends an admission, the patient or relatives may not agree to it; in this case, unless the patient requires compulsory admission, s/he will remain in the community. This illustrates Goldberg and Huxley's (1980) concepts of the different 'levels' in the evaluation process and the different 'filters' which operate on the patient in the

community with psychological symptoms from the decision to consult the GP, the GPs recognition of a psychological problem, the decision to request a psychiatric opinion, and on to the decision to admit. Help-seeking is, therefore, influenced by the patients' and carers' views of the symptoms.

Illness behaviour is primarily concerned with the first 'filter', the decision to consult the GP. Mechanic (1980) has identified the factors which influence the patients' or carers' perception of disease and their subsequent illness behaviour. The features of illness behaviour include: the perceived seriousness of the symptoms; their frequency, visibility and recognisability; knowledge about potential dangers arising from them; competing interpretations of the symptoms; individual thresholds to pain (or other unpleasant phenomena); disruption of normal routine; the presence of other needs which conflict with the need for treatment; the perceived availability of other forms of treatment; and the availability, proximity and costs of treatment and services. Obviously, in senile dementia the importance of each factor will vary. For example, a high proportion of those developing senile dementia will not have insight into their cognitive impairment, and even if they identify their memory as faulty, they may be more inclined to label it as the result of natural ageing rather than illness and so not seek help (Mechanic, 1991). In addition, the role of how formal or informal carers perceive the symptoms, illness, and need for help is vital, since they may also see it as part of ageing and so something which can neither be helped nor requiring the attention of doctors. A study by Reimann & Häfner (1972) showed that in the elderly with psychiatric problems, higher social class correlated with the frequency of consulting psychiatrists in free practice at an earlier stage in the illness, whereas lower social class correlated with a higher rate of admissions to the state psychiatric hospital at a more advanced stage of the illness.



In addition to the characteristics of the patients, certain characteristics of the general practitioner (GP) may influence the likelihood of requesting specialist psychiatric help. For example, previous psychiatric training may make GPs more confident about managing the elderly with psychiatric problems and less liable to feel susceptible to pressure from relatives to request a home visit by a consultant old-age psychiatrist (Orrell et al., 1992a). In addition, many GPs fail to recognise much of the psychiatric disorder presenting to them (Goldberg et al., 1980). Obviously if a psychiatric problem is not noticed by the GP they would be unlikely to refer to a psychiatrist, which would reduce or delay the likelihood of psychiatric admission. GPs, in particular, may have difficulty identifying psychiatric disorders in the elderly; there therefore tends to be a very low frequency of treatment for the patients (Copeland et al., 1992).

There are thus a number of factors relating to individual patients, relatives, and GPs which may make identification of a psychiatric problem less likely, and there are also factors influencing whether a referral is made and whether an admission is requested as part of that referral. Aspects of this decision-making process will be addressed in section 3.3.0 of the results, which deals with the consultation and admission process. There are also factors relating to the GP's views of the service with respect to the accessibility, helpfulness and competence of local psychiatrists and the difficulty of obtaining consultations and admissions. Lastly, because of some sort of acute crisis, there are other resources which the patient or carer may encounter before seeing a psychiatrist. These include social services, the accident and emergency services, and the police, who may be called to see individuals who appear to be at risk in a public place (e.g. nocturnal wandering).

In this way, the factors which influence the process from the patient's (or carer's) identification of symptoms to a psychiatric admission include those relating to: the patient and the carer (illness behaviour); the GP and the psychiatrist (clinician behaviour); and the local psychiatric and other services. Acute deterioration, therefore, is not the only factor which may be responsible for a patient becoming admitted.

In summary, theoretical arguments indicate that life events may have a role both in explaining the process of acute deterioration and also in the process and presentation of senile dementia.

This study seeks to examine the role of life events both in the acute deterioration and in the psychiatric admission of patients suffering from senile dementia, whilst taking into account the variety of other factors which may be influential (e.g. clinician behaviour).

In particular, because of the clear indications that social environment change may be disruptive to the dementia sufferer's functioning, it is necessary to develop a measure of routine and environment change which can be applied to life events. This will enable an investigation of whether life events with social environment change (routine and environment) is linked with acute deterioration and admission in dementia sufferers. In addition, considering the several studies which have linked threatening life events with depressive symptoms in the elderly and the high prevalence of depressive symptoms in dementia sufferers (Alexopoulos and Abrams, 1991), it is important to see whether such events are associated with depressive symptoms in dementia sufferers.



The results might have important implications for clinical practice, since if social environment change events lead to acute deterioration and admission this not only helps us understand the way dementia sufferers are affected by life change but also might suggest clinical strategies. The strategies might aim to minimise the frequency or buffer the effects of events thereby reducing the risk of admission (saving money) and might help to prevent the deterioration in symptoms, functioning and quality of life of the dementia sufferer. In addition, if threatening life events precipitate depressive symptoms in dementia sufferers, this has implications for screening and treatment. Identification of the effects of events could also help carers understand changes in mood and behaviour, and this in turn could reduce stress and guilt, and enable them to feel more able to cope if they are adequately supported.

This study is necessary in order to further our understanding of the effects of social factors in senile dementia. In so doing, it provides the next step in the process of research in the field and identifies future directions for study. The study is also necessary because by suggesting ways to improve the care of dementia sufferers and the support of their carers, it could have clinical implications. Lastly, it is necessary because the findings could potentially be used to help reduce the risk of admission.

In the design of the study it is important that the methodological pitfalls of previous work be avoided, as this would undermine the value of the results. For this reason, the problems of life events checklists are avoided by the use of the LEDS interview, a diagnostic interview is used to confirm cases and rate symptomatology (rather than just using clinician diagnosis), the CAPE BRS scale is used to assess dependency level, and a separate study evaluates clinician behaviour to control for psychiatrists' awareness of life events before admission.

# AIMS

## ***2.0.0 Aims***

1) To investigate the hypothesis that recent life events are related both to acute deterioration of senile dementia and the patient's presentation to services.

2) To investigate the hypothesis that deterioration in senile dementia is related to certain characteristics of life events, in particular to associated change in the patient's social routine and perceptual environment.

3) To develop new scales to measure the changes in social routine and perceptual environment occasioned by life events.

4) To investigate the factors involved in the decision-making process leading up to the admission through an independent assessment of the correspondence which preceded the admission.

5) To investigate factors which predict prognosis for the dementia patient group, over a two year follow-up period.



# METHOD

## ***3.0.0 Development***

An initial literature search revealed a lack of other research relating to life events and senile dementia, thus identifying an important gap in our current understanding of the disorder. In addition, as discussed in the introduction, there are theoretical reasons for believing that life events might in some way precipitate acute deterioration in individuals with senile dementia and that this might manifest by presentation of the patient to hospital psychiatric services resulting in an admission. A preliminary research protocol was successfully submitted for the six month research registrar post on the Maudsley Hospital's rotation, commencing on the 1st April 1988. During this time the pilot study was completed. The results suggested that the research merited expansion and development. In order to assess further the possible contribution of life events to the use of services and the course of the illness, a simple two year follow-up study was planned.

## ***3.1.0 Design***

### **Main study**

In order to look at life events in a population with senile dementia who had recently suffered some form of deterioration leading to an admission, the study group comprised senile dementia patients admitted as day or in-patients to a psychogeriatric assessment unit. To provide a comparison of the rate and qualities of life events in the normal elderly and to show the base line level of life events in a matched population, a community control group was chosen. It comprised mentally fit elderly subjects

matched for age and sex and chosen from the register of a local group practice. However, the frequency of life events in a stable community population with senile dementia is unknown, and it is possible that such a population may have a rate of life events higher or lower than that in the fit elderly. Because of this, the interpretation of results comparing only an admitted senile dementia population and a fit elderly population might be difficult and it would be difficult to know what conclusions could be drawn. This meant that a second control group comprising elderly community subjects with senile dementia was needed. This group should show whether there was any difference between the rate and qualities of life events in a stable community elderly population with dementia compared to the fit elderly controls and dementia patient groups. In particular, in order to ascertain whether life events precede deterioration in a patient population with senile dementia, it was necessary to know about the rate and characteristics of life events of a stable group of elderly subjects with dementia who were maintained with only community resources and did not need hospital admissions.

Since other factors apart from deterioration may be influential in precipitating the admission of a patient with dementia, it was also considered necessary to try and specify a date for deterioration. Where a deterioration date could be specified, life events during the three months before the date of deterioration were also enquired about. It was therefore possible to evaluate whether or not life events were associated with deterioration, and by considering only independent events it was possible to see whether life events appeared to *precipitate* deterioration rather than just reflecting the process.



### **Acute deterioration**

Since senile dementia is an illness which characteristically worsens over time, it was necessary to establish the degree of deterioration in all dementia sufferers. Therefore, in addition to dating the start of an acute deterioration, an overall assessment of the degree of deterioration was made for all dementia patients and dementia controls. This enabled an analysis to see whether greater deterioration was more likely to be associated with life events. The analysis was therefore able to control for high and low degrees of psychiatric deterioration prior to admission. During the informant interview, the deterioration was rated on a number of scales, including cognition, self care, mood and behaviour (see Appendix sections 7.1.1 and 7.1.2).

### **Pilot study**

The pilot study comprised 25 patients with senile dementia who had been admitted to a psychogeriatric assessment unit, and a fit elderly control group of 25 subjects randomly selected from the register of a local group general practice and matched for age and sex with the dementia patients. It followed the same methodology and interview procedure as the full study; for this reason these two groups were included within the equivalent larger groups in the analyses of the full study.

### **Factors leading to admission**

It was possible to argue that awareness of life events may have influenced the referrer's or the consultant's decision-making process. This was because the clinicians might have had a particular bias towards admission if a life event had occurred which suggested to them that the person would be unable to cope. This would mean that if

an association between life events and admission was found, it could be argued that this was due to *clinician behaviour* rather than the deleterious effects of life events. To control for this possibility, an independent evaluation of the factors leading to admission was carried out by an observer blind to whether or not the patient was admitted. The psychiatric correspondence prior to the admission was rated by the observer to determine the relative influences of physical, psychiatric, and social factors on the decision of the psychiatrist to admit. The observer also looked for any life events noted in the correspondence. Finally, the observer was asked to list the factors which were associated with a need for admission in each case.

### ***3.1.1 Sample***

#### **Dementia patient group**

This comprised 70 patients with senile dementia admitted as day or in-patients to a psychogeriatric assessment unit. In order to select appropriate patients for this study the investigator made frequent visits to the Felix Post Unit at the Maudsley Hospital and Gresham I Ward at the Bethlem Royal Hospital, the two psychogeriatric assessment units covering the South Southwark catchment area. The patients admitted were under the care of one of the three Consultants on these units. The investigator went through the admissions book and the current patient lists with the nurse in charge to identify any patients who had possible dementia or cognitive impairment of note. In addition, the investigator spoke to the current junior doctors on the units and enquired about any patients they had admitted who were suffering from possible dementia. At this stage of the enquiry, patients who were not included either suffered from some well-defined diagnosis other than dementia or had no notable cognitive



impairment, or both. The investigator went through all the sets of notes of the remaining patients (who possibly had senile dementia) using the inclusion and exclusion criteria set out below to establish whether or not they would be suitable for the study. Although Consultant diagnosis was used as one of the entry criteria, this had to be supported by the cognitive test score and validated by the investigator using the GMSS semi-structured interview.

### **Inclusion criteria**

- 1) A Consultant diagnosis of primary degenerative dementia.
- 2) A score in the cognitively impaired range on the Mini Mental State examination (Folstein et al, 1975) or on another recognised brief test of cognitive function (Orrell et al, 1992b) (see Appendix section 7.1.2).
- 3) The availability of a suitable informant.

### **Exclusion criteria**

- 1) Psychiatric admission in the last year.
- 2) severe physical illness which might affect cognitive function (e.g. stroke, liver failure) (see Appendix 7.1.2).

All patients and their informants who were included were interviewed within a maximum of four months from the date of admission. This period was chosen for two reasons; first, it was often necessary for patients to spend some time as an in-patient or day patient in order for a definitive diagnosis of primary dementia to be established; and second, it was important that informants were only expected to recall life events

within the previous year because of the problems of accurately recalling events accurately further in the past. A maximum four month period before inclusion in the study together with the need for the informants to recall life events over a six or eight month period of time, limited the total period of recall to a maximum of 12 months. In practice, most patients were seen well within the four month cut-off period.

### **Fit elderly control group**

These comprised 50 elderly subjects selected randomly from the register of a local group general practice in South East London (Forest Hill Road, SE22) and matched for age and sex with the first 50 patients from the dementia patient group. The investigator had access to the practice case register, and after random selection of subjects of the correct age and sex to match with the study group, he discussed the proposed subjects with one of the general practitioners (usually Dr Helen Graham) and referred to the case files to establish whether or not they were suitable for inclusion in this study as defined by the exclusion criteria below. It was also necessary to check that the person was alive, still in the area, and not currently suffering from any known psychiatric illness.

### **Exclusion criteria**

- 1) Current psychiatric illness.
- 2) Psychiatric admission in the last year.
- 3) Severe physical illness which might affect cognitive function (e.g. stroke, liver failure, alcoholic brain damage).



Psychiatric patients were excluded because of the relationship between psychiatric illness and life events and in order to provide a more homogeneous comparison group.

The investigator liaised with Dr Graham or Mrs Pat Claxton, the practice manager, as the need arose. This practice has a large (20,000+) socially mixed population, including parts of Peckham and East Dulwich, a catchment area which was similar to that for the dementia patient group and the dementia control group. These factors made it an appropriate sampling frame from which to draw this control group. The investigator wrote to the selected controls offering them an interview by the investigator at home at a specified date and time. A stamped addressed envelope was enclosed for reply. If no reply was received one or two days before the interview was due to take place, the interviewer would ring the person at home to see if they were agreeable to participating in the study.

### **Dementia control group**

This comprised 50 elderly subjects in the community with primary dementia. These people were selected from the Holmhurst and Evelyn Coyle Day Centres. Subjects were either currently attending or on the waiting list of one of the centres. These two day centres provide a service for the elderly suffering from dementia to help support them and their carers in the community. The inclusion and exclusion criteria were designed to select only those people who had been relatively mentally stable in the previous six months and who had therefore not required any kind of admission to hospital psychiatric facilities. Brief respite periods for the senile dementia sufferer in elderly people's homes did not exclude them from this part of the study, since it was

considered that such respite care was an integral and essential part of good community services for dementia sufferers, which enabled their carers to have a break and also to continue to look after them at home. Individuals currently in permanent residential care were not included in the study because, on the one hand, they were not attending day centres and, on the other hand, since their care was fully supervised they could not be construed as being able to survive with support in the community. In addition, they were to an extent protected from some of the potential effects of life events.

Before the selection process began, the investigator arranged informal visits to speak to the managers of each of the two day centres and to meet the rest of the staff. Both of these day centres had close links with the Maudsley Hospital, since they served the same catchment area. The selection process involved the investigator going to each of the day centres and working through the list of people currently attending, checking each of the specified selection criteria with the day centre manager. In addition, the case files at the day centre were examined to assess physical health and discover the consultant diagnosis. All day centre attenders had been assessed by a consultant old age psychiatrist as part of their assessment procedure (if they had not already been assessed by the psychiatric services). At this stage it was usually obvious whether or not the individual had had any recent psychiatric admissions; this information was requested during the informant interview and, if necessary, subjects were excluded from the study at this point. After subjects had been selected, the identified informant was written to and invited to attend the day centre for an interview. A date and time for the interview were specified and a stamped addressed envelope for reply was included with the letter. In addition, if the informant had not confirmed the interview



date, either by ringing the day centre, returning the letter to the day centre, or contacting the investigator directly by telephone, the informant would be rung in order for them to confirm, change, or cancel the appointment.

### **Inclusion criteria**

- 1) A Consultant diagnosis of primary dementia.
- 2) A score in the cognitively impaired range on a test such as the Mini Mental State.
- 3) The availability of a suitable informant.

### **Exclusion criteria**

- 1) Psychiatric admissions in the previous six months.
- 2) Severe physical illness which might affect cognitive function.
- 3) Unlikely to be able to continue coping in the community for the next three months without needing psychiatric admission or permanent residential or nursing home care.

In order to avoid including subjects who were already deteriorating significantly, the day centre manager and informant were asked if they thought there were likely prospects of the subject being admitted to some form of institutional care within the next three months. If so, the subject was excluded from the study on the grounds that they had deteriorated, or were soon likely to deteriorate to such a point where they would no longer be able to cope in the community even with additional support and facilities. As such they would not be appropriate controls for the study: this control

group was needed to provide an estimate of the rate of life events in a stable community dementia population, as a population who were deteriorating significantly might be doing so as a result of experiencing life events.

### **Informants**

An informant was defined as a close friend or relative, either living with the subject or in regular contact at least weekly and able to give an accurate account of the subject's life events over the last year. In a 20% sub-sample of the fit elderly control group, informants were also interviewed about life events relating to the person selected as a control. This was to assess the accuracy of the informants' life event history. Previous research (Murphy, 1982) has shown that informants are indeed able to provide an accurate history of life events in the elderly.

### ***3.1.2 Instruments and other data***

Information was gathered from a number of sources including subject interview, informant interview, medical and psychiatric notes, and discussion with staff who were involved. In the fit elderly control group the subject provided all the information, but for a proportion of them an informant was also interviewed separately about life events (to cross check the reliability of using an informant interview). For the dementia patients and dementia controls the subjects were interviewed using the GMSS diagnostic interview and the informants were interviewed about life events, acute deterioration, CAPE score and other information. In addition, where necessary (and available) information was also provided from case notes and from speaking to staff who were involved. Sometimes the key informant (usually a relative) could provide



adequate data on life events but was less aware of the day-to-day functioning of the person. When this occurred, an additional informant (often the warden, home help or CPN) was interviewed in order to complete the data set. If it was not possible to get adequate information, the subject was excluded from the study.

### **Geriatric Mental State Schedule (GMSS)**

This is a semi-structured clinical interview for the assessment of diagnosis and mental state in the elderly (Copeland et al., 1976). It has been extensively tested in the UK and USA, and has been shown to be a valid and reliable instrument in the hands of trained investigators (Copeland et al., 1976; 1986; 1987; 1992). The GMSS can identify cases and grade cognitive impairment, and other psychiatric symptoms such as depression and anxiety. It is useful in both hospital and community samples (Copeland, 1990). Used clinically it can provide reliable diagnosis, and it can also be analysed using the AGECAAT computerised diagnostic system (Copeland et al., 1986). The AGECAAT provides a computerised diagnosis and also ratings of severity for symptoms in the following eight categories:

- Organic (cognitive impairment)
- Schizophrenia/Paranoia
- Mania (elated, irritable or 'other')
- Depression (psychosis, neurosis or undifferentiated)
- Obsessional Neurosis
- Hypochondriasis
- Phobia
- Anxiety

The GMSS was used in preference to the CAMDEX (Roth et al., 1986) for a number of reasons. Firstly, at the commencement of the study in 1988 the GMSS was a well-established instrument, whereas the CAMDEX had only been published relatively recently and thus had more limited reliability and validity data available. Secondly, there was not thought to be a need for such intensive detail about cognitive function as elicited by the CAMDEX, the needs of the study being adequately provided for by the cognitive tests of the GMSS. Lastly, the GMSS had a range of different scales covering a variety of psychiatric symptoms.

#### **Bedford College Life Events and Difficulties Schedule**

The Bedford College Life Events and Difficulties Schedule (LEDS) is a method of identifying and gathering relevant information on life events and difficulties using a semi-structured interview which covers a full range of aspects of life experience (Brown and Harris, 1978). As has been discussed in the introduction, this is much preferable to the various checklist methods. Life events were rated by a panel of trained raters (Paul Bebbington, Brigid MacCarthy) according to the degree of 'threat' and 'independence' using the contextual rating method of Brown and Harris. This reduces the possible bias which may occur if the person who performs the interview also tries to rate the life events for threat and independence; it also means that the bias of the subject's own feelings about the particular importance of the life event can also be reduced. The LEDS is reliable even when used by raters who have only had brief training (Tennant et al., 1978; Parry et al., 1981). It is also an accurate and reliable method for eliciting and recording life events in the elderly population (Orrell and Davies, 1994). Finally, the reliability of eliciting life events using informant interview,



which is an essential prerequisite for this study, has been demonstrated for the LEDS (Murphy, 1982). In the process of eliciting events it was important to specify the precise date of the event. This was done by carefully asking the person when the event happened in relation to key dates (e.g. Xmas, birthdays, anniversaries) and when it happened in a particular month. By prompting the person to recall experiences around the same time it was possible to date the events precisely.

#### Life events before admission

In order to quantify the life events the calendar dates were converted into Julian Dates. Julian Dates can be added and subtracted to define any set time periods. The study covered the period six months before a key date: admission in the case of the dementia patients and interview in the case of the control groups. In order to calculate the interval between the key date and the life event, the date of the latter was subtracted from the date of the former. This gave a period in days, which was then divided by seven to convert to weeks for convenience of data manipulation.

#### Life events before acute deterioration

The informant for each dementia subject was asked to give a precise date for the onset of the patient's deterioration if it had started within the six months prior to admission. This was to enable life events in the three months directly before this deterioration date to be compared with a similar three month period in the life event records of both of the control groups. The period six months prior to admission was chosen for two reasons: first, the deterioration had to be able to be defined as acute; secondly, the six

months plus three months totalled a maximum of nine months over which the informant would be asked to recall life events.

As has been argued in the introduction, there was reason to think that disruption of the social environment might be a key factor in how life events might precipitate deterioration in dementia sufferers. With this in mind, new scales were developed to score life events for changes in routine and in environment (Orrell et al., 1990). Assessments were made of the extent to which events implied a disruption of the care or support the elderly person was receiving (as described in section 3.2.0). These scales were shown to be reliable when used by raters after brief training.

#### Life events and carers

Life events were specifically addressed in this study for a number of methodological and theoretical reasons. First, in common with other life events studies, this study was designed primarily to examine how life events affected the individual sufferer rather than carers, or people who have a greater or lesser role in the subject's life. This was also a matter of principle, since the researcher considered that a disproportionate amount of psychosocial research had been undertaken with carers compared with the number of studies on senile dementia sufferers. Secondly, if a carer's life events affect the sufferer, this effect would be primarily through a disruption of the caring process associated with life events. This disruption was already being measured by the routine and environment scales. Thirdly, if a carer had life events which also had an impact on the sufferer, those events would in any case be rated as events for the sufferer. Fourthly, not every carer had the same degree of involvement with their particular



dementia sufferer. Some carers were cohabitees, others lived nearby, and others lived some distance away. In many cases multiple carers were involved. Thus, there would have been serious methodological problems involved in trying to weight for the degree of involvement for each carer and the level of impact of event on each carer. These problems seemed not only unnecessarily complex but inferior to the methods being used and detrimental to the overall quality of the study. Lastly, there was no evidence from previous work that the carer's life events *per se* also affect the senile dementia sufferer.

**Clifton Assessment Procedure for the Elderly (CAPE) (behavioural assessment schedule)**

Using information from an informant, this is a valid and reliable standardised method for assessing a wide variety of areas of behavioural functioning in the elderly (Pattie and Gilleard, 1979). Questions include one on vision and one on hearing, plus 18 covering four areas of behaviour and dependency:

- physical disability (6 items, 0-12 score)
- apathy (5 items, 0-10 score)
- communication difficulties (2 items, 0-4 score)
- social disturbance (5 items, 0-10 score)

The questions on behaviour and dependency give a total possible score of 36 (each scoring 0-2). The overall score gives a rating of severity of dependency, and has also been shown to be an indicator of appropriate placement, prognosis, and survival in elderly psychiatric inpatients (Pattie and Gilleard, 1978). It can also predict outcome

and survival in elderly psychiatric day patients and attenders at psychogeriatric day centres (Bell and Gilleard, 1986).

### **Quality of the relationship with cohabitee**

If the subject had a cohabitee, a brief assessment of the current state of their relationship was made using the scales developed by Bergmann et al. (1984). This method was chosen because it is brief, easy to administer, and because the quality of the relationship according to these scales has been shown to predict outcome in patients with dementia who have carers. This suggests that the scales have predictive validity. The subject's relationship with the carer is assessed on three seven point ordinal scales:

- Dominance-Submissiveness
- Negative-Positive communication
- Autonomy-Dependency

For example, on the Dominance-Submissiveness scale, a score of 1 would occur where the subject controls every aspect of the relationship, and a score of 7 would occur where the carer controls every aspect of the relationship. A rating of 4 would indicate an equal sharing of control and a balance of power, whereas a score of 5 would indicate that the carer was mainly in control but that there were some areas where the subject had a lot of control.

The full scales are given in the appendix, section 7.1.3



**Demographic and other data:**

- Age
- Sex
- Diagnosis
- Educational level
- Previous occupation and social class
- Past medical history
- Current physical health
- Level of disability
- Family history of psychiatric illness or alcoholism
- Past history of psychiatric illness or alcoholism
- Social situation

**Accommodation**

The type of accommodation and any problems with its condition were noted (e.g. dry rot, building work, ceiling collapse, severe neglect, dilapidation). This was rated on two five-point scales, one assessing the state of structural condition, and the other the superficial condition (in terms of hygiene, need for redecoration, etc.).

**Current social support**

This included home help, meals on wheels, day centres, voluntary help, support by the carer, and the degree of involvement of other professionals such as the district nurse, social worker and community psychiatric nurse. Each of these was rated on a five-point scale corresponding to the number of days-per-week help from each type of care.

This method was chosen in preference to more complex methods of evaluating social support because it was simple and easy to apply, and did not seek to make assumptions that social support for senile dementia sufferers was exactly the same as that for mentally fit elderly or depressed elderly. For example, 'social support' can imply a confiding relationship and therefore relatively uncompromised verbal and comprehension skills; however, these are just the sort of areas in which people with senile dementia often have problems. The method used in this study was based on input of social contacts and social care rather than the interpretation of the quality of that input in terms of the relationship. As such, although it may be simpler, it also makes fewer assumptions.

Social support and degree of isolation were also assessed by recording daily and weekly social contact. If the person had more or less *continual* contact all day (for instance, if they lived with their spouse) they rated the *maximum of 8* (for one day). If the subject spent periods of time with other people, one point was scored for every social contact of up to an hour during the day (i.e. one day at a day centre would rate 5 points = 5 hours). Total social contacts were estimated for each weekday, weekend and full week by adding up the approximate number of social contacts in each time period.

The number and status of cohabitees were recorded (i.e. wife or other relative, friends etc.). In addition, the nature of the relationship of the informant to the subject was recorded. In practice the informant was usually a relative or close friend or neighbour who was in regular contact and who fitted the definition of informant already



described. It was sometimes necessary to speak to several individuals to get all the information. For instance, a warden may have a better idea about the current problems, and a relative may provide a better life events history. In these cases the person who provided the life events history would be recorded on the form as the informant.

Information on the family network was collected. A family tree was drawn, and the following information on other people in the family was identified: the age, sex, whereabouts and involvement with the subject.

The informant was then asked to identify the onset of the dementia; s/he was asked for the very first signs which suggested to them that the subject was suffering from any kind of mental deterioration. Where necessary, the investigator provided information on some of the possible early signs of dementia. Having identified the probable first indications of the dementia, the investigator then asked the informant to try and date the onset of the early signs. Often the informant could make a reasonable estimate of the date of the onset by using relevant anniversaries or specific times of the year (such as Christmas) to jog their memory. A best estimate of the time of the onset of the illness was made, based on the investigator's assessment of the informant's description.

#### **Assessment of acute deterioration**

The informant was also asked whether there had been any period of acute and significant deterioration in the subject's mental condition during the last year, and if so to date it accurately (see method for dating life events), or whether the subject's

illness had progressed gradually without any specific period of increased deterioration. Following this, an assessment of the degree and qualities of the subject's deterioration over the past year was made, using a number of new scales (see appendix sections 7.1.1 and 7.1.2). These scales assessed changes in mood, behaviour, cognition, self care, sleep disturbance, incontinence and other problems. Some of these scales resembled certain features of the CAPE (such as cognitive problems). However, the CAPE measured current state and the acute deterioration scales measured various aspects of recent deterioration (over the preceding six months). *No deterioration* was rated as 0, *mild* as 1, *moderate* as 2 and *severe* rated 3. This simple scale was intended to measure the different qualities of deterioration identified by the informants, and in addition to provide corroborative evidence of the course of the disorder. In this way, the analysis could control for high and low degrees of psychiatric deterioration prior to admission.

### **Date of onset**

Dating the onset of dementia was usually not as accurate as dating life events or deterioration because the retrospective time period was usually very much longer. This meant that informant's recall was not as good and they often found it difficult to date the first symptoms with accuracy. The researcher prompted their recall by asking for the very first things that they noticed which suggested that the person's memory (for example) was beginning to fail or the first change in behaviour (such as loss of interest in reading). The researcher also dated the onset as accurately as possible using the methods described above for dating life events.



### **3.1.3 Procedure**

The initial idea for the study was formulated in summer 1987; a protocol was drawn up and revised. The data collection began on 1st April 1988. With the further development and expansion of the study, the selection and interviewing of subjects was finished in October 1991. All aspects of the study were carried out by the investigator except where specified.

#### **Training**

Training in use of the Geriatric Mental State Schedule (GMSS) was provided by Dr Forshaw from the Institute of Psychiatry, who is a recognised trainer and worked with Professor Copeland on the schedule. The training programme involved discussion of the GMSS and the GMSS manual and the co-rating and discussion of 10 psychogeriatric patients with a variety of organic and functional diagnosis. Training in the Bedford College Life Events and Difficulties schedule was provided by Dr Bebbington. Supervision in statistics was provided by Dr Graham Dunn and Professor Brian Everitt of the Department of Biometrics at the Institute of Psychiatry. Mr Geoff Der of the MRC Social and Community Psychiatry Unit provided expert advice on computing.

#### **Interviews**

The assessment of each subject, including time for travelling and administration, required approximately two to three hours. The interviews of the subjects with senile dementia usually took place at the Maudsley or Bethlem Royal Hospitals. If the subject was no longer an inpatient or had finished attending the day hospital, they were

usually interviewed where they lived. The informants were either interviewed at one of the hospitals or at home, according to their preference and convenience. The interviews with the fit control subjects usually took place in their own home, but they were also offered a choice of seeing the interviewer at the Forest Hill Road General Practice or at the Maudsley Hospital. The dementia controls and their informants were often seen at the day centres, but people were offered the alternative of being interviewed at home or at the Maudsley Hospital. Interviews usually took place within working hours, but sometimes had to take place in the evening or at weekends.

### **Data processing**

The individual records for each of the 170 subjects were thoroughly checked by the investigator for completeness and consistency. They were then sent to a data encoding company for transcription on to floppy disc. The investigator prepared a carefully marked sample data package and explanation sheet for the data encoding company, and also rang them on several occasions in order to check that they clearly understood the guidelines and were putting the data on disc correctly. The investigator had past experience of the quality of this company's work and also had the recommendation of another researcher who had used them. The data encoding company routinely used two workers to transcribe the data independently onto disk, cross-checking to identify any discrepancies, which made it possible to ensure that the data had been processed correctly. On receipt of the floppy disk, the investigator checked the layout and quality of the data and found it to be satisfactory.



At this point the data from the Geriatric Mental State Schedule were extracted and sent for analysis by Dr Mike Dewey on the AGE CAT computer programme at the University of Liverpool. This programme provides a computer-assisted diagnosis and scores the severity of a number of aspects of the mental state, including organic symptoms and signs, and depressive symptoms and signs.

### ***3.2.0 Life events: measuring changes in routine and environment***

#### **New scales**

These scales were developed to measure changes in the subject's social *routine* and perceptual *environment*. They were designed to measure the impact of an event on an individual's daily life, in particular its potential effect in causing confusion. Certain events may be judged to have no direct effect on the quality of daily life, but may still be 'independent' (of an individual's sphere of influence) and involve a high degree of 'threat' to the person's well-being. An example of this might be the death of a sibling with whom the subject now has little or no regular contact except by letter or telephone. Such an event would involve a 'threat' but no change in the subject's regular routine or immediate environment. Likewise, disruption in the environment or routine of an individual's daily life may not involve a life event of much ostensible threat. Measures of change in routine and environment are therefore conceptually distinct from the 'threat' attributable to a life event, although there is likely to be a degree of correlation.

*Change in routine* is primarily concerned with personal contacts in the subject's daily life, such as regular visitors. These contacts would include, for instance, a home help

or other support staff such as a warden. If one of these key people stopped attending, through illness or a change of job for example, it would constitute a *routine change*, the severity of which would be determined by the relationship with the subject and the contribution to the subject's routine. Regular structured activities outside the home, such as attendance at a day centre or luncheon club, were also rated.

*Changes in environment* might involve a move, a holiday, etc., or even major structural damage or repairs to the home. If the subject regularly spent a substantial proportion of the week in another place such as a day centre or someone else's home, a change in this could also be regarded as a change in environment, the rating of which would depend essentially on the time spent there. Sometimes changes in environment and routine will occur together, for example the closing of a day centre which the subject had been attending.

### **Procedure**

As part of the pilot study (section 3.1.0), the life events experienced by 25 elderly senile dementia patients in the six month period prior to their admission to hospital were elicited from a close informant. A history of events was also elicited from 25 fit elderly control subjects. The interviews were based on the Bedford College Life Events and Difficulties Schedule (Brown and Harris, 1978). The life event histories were used to prepare the vignettes used for the reliability study of rating changes in routine and environment.



The degree of 'independence' and severity of 'threat' were measured in the usual way by the independent raters Paul Bebbington and Brigid MacCarthy. Guidelines for the ratings were drawn up (see Appendix 7.2.0 and 7.2.1), and ratings were then made by Martin Orrell after discussion with Paul Bebbington.

In order to investigate the reliability of life event ratings based on the use of the finalised guidelines, two inexperienced raters were recruited (Naomi Elton and John O'Brien). Both were psychiatric trainees at the Maudsley Hospital with at least a year's experience in psychiatry, including psychogeriatrics. Neither was familiar with the two new scales, or had experience of rating life events. The new raters were given the guidelines to read in advance, together with a series of subject vignettes (a mix of patients and controls) giving an outline of the physical health and social situation of each subject. In particular, the relatives, friends, other carers and support services were mentioned. The raters were blind to the subjects' psychiatric status. Descriptions of six life events were provided, with details of all the ratings made (threat, independence, routine and environment).

A training session of 45 minutes then took place, during which the principles of the guidelines and the rating of the examples were discussed. In the latter part of the session the raters (NE and JO) were given a further six life event examples to consider, and asked to rate them for changes in routine and environment. At the end of the training session, the raters discussed their results with the trainer (MO), who clarified any discrepancies so that a consensus on the ratings was achieved.

The new raters were then given copies of more subject vignettes, comprising 30 life events, to rate for routine and environment change. They were provided with the ratings for threat and independence for each event, but once again were blind to whether the subject was a patient or control. The raters were instructed not to confer. All 30 life event ratings were completed by both novice raters. Standard ratings had been made by one of the experienced raters (PB) who was blind to all the previous ratings. The ratings of PB were then used as the benchmark comparison to determine the reliability of the new scales of routine and environment change with respect to the new raters. The points of the scales are shown in tables 3.20A and 3.20B.

**Table 3.2.0A - Routine change - EXAMPLES AND RATING SCALE**

- 4 = Extreme Permanent loss of carer living with subject.
- 3 = Severe Loss of carer attending three or more days per week or closure/loss of day centre. *Duration - two weeks or more.*
- 2 = Moderate Loss of carer or visitor attending one or two days a week or loss of one or more days' attendance at a day centre. *Duration - one month or more.*
- 1 = Mild Loss of any other visitor/carers/friend with whom the subject has regular contact (weekly). *Duration - one month or more.*
- 0 = None No change in routine.



The various degrees of change in routine and environment formed an ordinal scale. The duration for each rating point was chosen in relation to the overall disruptiveness it was considered to have on an elderly person's daily life. This was partly based on the past experience of the investigator working with the elderly. One month was considered the standard duration. However, for certain particularly disruptive routine or environment change events a shorter period seemed more appropriate. In particular, for 'severe' routine change, two weeks seemed to be long enough to warrant this level of rating (see case vignettes in Appendix 7.2.1). This was in view of the considerable amount disruption to the sufferers life resulting from such a change.

**Table 3.2.0B - Environment change - EXAMPLES AND RATING SCALE**

- 4 = Extreme Permanent move to worse accommodation or new area unknown to subject.
- 3 = Severe Other permanent or long term move. *Duration - one month or more.*
- 2 = Moderate Temporary move, e.g., holiday, respite care, hospitalisation, or stay with relatives. *Duration - more than three days and less than one month.*
- 1 = Mild Changing to a different room in the home. Major structural alteration or damage in the home. Loss of regular visiting to another environment (for example, day centre). *Duration - one month or more.*
- 0 = None No change in environment.

### ***3.3.0 Factors influencing admission and referrer's awareness of life events***

This part of the study examines the possible factors which may influence the decision-making process leading to admission. The main objectives were:

- 1) To identify life events in order to control for knowledge of events that may have influenced the psychiatrist's decision-making process.
- 2) To ascertain the reliability of the acute deterioration rating score.
- 3) To investigate factors leading to admission.

Since in this study admission has been considered to be one indicator of deterioration, it was important to know whether life events influenced the decision to admit (even when other factors known to be important in the process of admission such as psychiatric and physical deterioration were taken into account). The reason for this is that if life events specifically influenced the psychiatrist towards an admission, the admitted population are not necessarily a deteriorated population. If so, admissions may reflect clinician behaviour rather than deterioration in the dementia patient. In this investigation it was possible to ascertain the proportion of life events known to the doctor who was making the decision to admit. Thus, it was possible to make comparisons between life events known to the referrer and the admitting psychiatrist which could have influenced the decision making process, and the total number of life events as established by the investigator's interview with the informant.



If the results indicated that awareness of life events made a significant contribution to the psychiatrist's decision to admit the patient, this might suggest that it was life events rather than deterioration which led to admission. Whilst this would be an important finding in itself, it would also have serious implications for the interpretation of the main study, which assumes admission to be related to some degree of acute mental deterioration. If the results indicated that life events did not contribute significantly to the decision to admit, this would suggest that deterioration was the overriding cause of admission. In this case, either the doctor's decision was not significantly influenced by an awareness of the patient's life events or the doctor was unaware of them.

## **Procedure**

As an assessment of the factors leading to admission, the psychiatric correspondence prior to the admission was rated to determine the relative influences of physical, psychiatric and social factors on the decision to seek help and the decision to admit. The full psychiatric notes could not be used as a substitute because at that point the decision to admit had already been made. The clinical correspondence in the six months before admission for the patients admitted with senile dementia in the main study was examined by the primary rater Dominic Lam (DL) to investigate possible influences on the decision to admit. DL was a researcher and clinical psychologist experienced in working with the elderly and trained in the assessment of life events. He was trained in the other ratings by the investigator (MO) who had developed the ratings package (derived from the larger study). This involved discussion and clarification of the protocol and rating guidelines, followed by joint ratings and

discussion of correspondence from ten cases not used in either study group (A or B) listed below. After this training period, the primary rater and researcher each rated the cases independently to assess reliability for the core measures. Apart from the initial training period the raters were blind to whether or not the patient was admitted as a result of the assessment.

The letters assessed in the study itself were drawn from the following sources:

**Group A** - 50 from a study of life events in senile dementia

(rated by DL only).

**Group B** - 80 from a study of domiciliary visits by old age psychiatrists

(rated by DL and MO).

#### Group A

This group was drawn from the 70 patients in the main study admitted with senile dementia. Not all of these had correspondence before admission, and in some the correspondence was in the form of a hand written note. Approximately 15 patients were excluded for reasons of inadequate correspondence. The correspondence of a further five patients was used for the purposes of training the two raters (DL and MO) and developing the rating sheets. This left the 50 patients who could be used in the study (see above).



## **Group B**

This group was selected from 100 sequential consultant old age psychiatrist's domiciliary visit assessment letters from a different catchment area to the main study. Not all were used as some were inadequate for rating, and another five had been used in training the raters and developing the rating sheet. This group was included for two reasons. Firstly, in order for DL to be blind to the outcome in terms of admission, we needed a similar batch of correspondence relating to domiciliary visits not all of which had resulted in admission. Secondly, by getting both DL and MO to rate these letters it was possible to compare the reliability of the measures of acute deterioration as used in the main study and the identification of life events from the correspondence.

## **Data collected**

From all the letters, names and identifying features, plus details of the patient's admission (or not), were deleted. This meant that the raters would not know the source or outcome of the correspondence when making their ratings. Raters were required to judge the likelihood of admission as a result of the assessment, and to list the factors in the assessment that were most likely to lead to admission.

The rater estimated the relative influences of physical, psychiatric and social factors on the decision of the general practitioners to seek help and the decision by the psychiatrist to admit.

For the total 130 (50 + 80) elderly psychiatric patients, the specialist psychiatric assessment letters to the general practitioner were examined and rated on the following: (Appendix 7.3.0, 7.3.1, 7.3.2)

- Educational background
- Social class
- Physical illness
- Psychiatric history
- Accommodation
- Social support
- Recent life events
- Acute deterioration in psychiatric symptoms

The rater also noted any life events mentioned in the correspondence and assessed their degree of independence and threat. Life events were rated according to the Bedford College Life Events and Difficulties Schedule (LEDS) method in which both raters had been trained.

Although the rater may have had difficulty in completing the scales for the LEDS in cases where the information given in the letter was inadequate to make a proper contextual rating, this was considered to be the best method for making comparisons between the raters, and certainly preferable to a checklist. It also had the advantage of being the method used in the main study.



### ***3.4.0 Follow up of senile dementia patients***

Between two and three years after their admission the first 60 patients in the study group were followed up. This allowed comparisons of outcome to be made between subjects according to:

- 1) Their life events experience before admission
- 2) The severity of dementia
- 3) The presence of mood symptoms
- 4) Levels of social support
- 5) The use of hospital, nursing home, residential home and other facilities

The current situation of each of those subjects in the study group who had previously been admitted with senile dementia was established. The investigator looked through psychiatric, medical and day centre notes, and also rang, and (where necessary) visited the current residence of the subject in order to complete the follow-up data collection.

The procedure involved speaking to someone who was currently involved with the care of the subject and other informants such as relatives in order to establish the overall course between the date when the subject was seen for the main study and the date of follow up.

This allowed a picture to be built up of the subject's health and service utilisation over the whole follow-up period.

Data were collected on:

- 1) Dates and duration of psychiatric admissions
- 2) Dates and duration of other hospital admissions, together with medical diagnosis
- 3) Dates and duration of periods of residential care
- 4) Dates and duration of periods of nursing home care
- 5) Dates and duration of day centre attendance
- 6) Current residence (if applicable)
- 7) Date and cause of death (if applicable)

With this information it was possible to carry out a prospective follow-up study plotting the course of each subject through the system of care to establish which factors were related to a high dependence on hospital and other services, and which appeared to be related to longer life and better physical health. Using information from the main study, it was possible to control for previous physical ill health and, to a certain extent, for degree of family and carer support.



### ***3.5.0 Statistical analyses***

The analysis of results was carried out using SPSS/PC+ Version 4.0. Standard analyses included: Chisquare ( $\chi^2$ ), Fisher's exact test, Spearman's correlation, the t-test and Cohen's Kappa. Since these tests are well-known, a detailed explanation in this test is unnecessary. Relative risk and odds ratios were calculated according to Everitt (1992). Survival analysis was carried out using SPSS and the discussion of it referred to Armitage and Berry (1987)

Power analyses suggested that if the control group had a true life event rate of 20% and the dementia patient group had a true life event rate of 40%, a sample size of 50 per group gave a 95% chance of demonstrating this difference at the  $p < 0.01$  level.

#### **Logistic regression**

For multivariate analyses, logistic regression was used. This was chosen because it selects which variables best differentiate between the two values of the dependent variable (0 and 1) and the relative contributions of each. Unlike many other methods, it can use a mixture of continuous and categorical variables. It also requires fewer assumptions than linear discriminant analysis, and performs well even when the assumptions required for discriminant analysis are satisfied. The logistic regression procedure *'builds logistic regression models which are used to estimate the probability that an event occurs. It allows user specified entry of variables into the equation as well as both forward and backwards stepwise entry. ... The subcommands for residual analysis help detect influential data points, outliers, and violations of the model assumptions.'* (Norušis/SPSS inc., 1990).

The regression coefficients for each independent variable are expressed as a log odds ratio for the specific independent variable, changing the value of the dependent variable from 0 to 1. Entering the variables either singly or in groups, the probability of an individual variable contributing to the overall model is determined using the Wald statistic (which is the square of the ratio of the coefficient over the standard error of the coefficient) which gives a value for the residual chi squared. Using a histogram to illustrate how well the overall model classifies the observed data is one way of determining how well the logistic model performs. Another way of assessing the goodness of fit of a model is to examine how likely the model is to fit the results (this is known as the *likelihood*). This is a small number (less than 1) and it is customary to use -2 times the log of the likelihood (-2LL) as a measure of how well the estimated model fits the data because -2LL follows a  $\chi^2$  distribution if the model fits the data. A good model is one that results in a high likelihood of the observed results and gives a small value of -2LL. A perfect model would give a likelihood of 1 and a -2LL of 0. The *improvement* is the change in -2LL between successive steps of building a model, and tests the null hypothesis that the coefficients for the variables added at the last step are 0. The value of the improvement is known as the *improvement chi square*, comparable to the F-change test in multiple regression. Variables which make the most significant contribution to the overall model will have high values for the improvement chi square, which can be tested against the conventional significance level of 0.05.

In logistic regression, the SPSS program allows each or any combination of the variables to be entered in turn, and controls for the variables already in the model.



Using a forward stepwise selection procedure, each of the variables with the smallest significance level is entered into the model. Each variable is then examined to see if it meets the removal criteria as defined by the *likelihood ratio* and, if so, the variable is deleted, resulting in a model which meets the twin requirements of parsimony and goodness of fit. The likelihood ratio test involves estimating the model with each variable eliminated in turn and looking at the change in the log likelihood when each variable is deleted. Once more -2LL can be calculated and compared with the chi-square distribution. When the likelihood ratio is used for removing terms from a model its significance level is compared to the conventional cut-off value (0.05).

In this way, using logistic regression to look at subjects with senile dementia with and without depressive symptoms, it is possible to estimate the effects of life events in precipitating such symptoms while taking into account other variables which may contribute to the occurrence of depressive symptoms.

# RESULTS

## 4.1.0 Pilot study

The report of the results of the pilot study will be confined to simple comparisons of the number of life events in the study group and in the control group. This is because the numbers in the pilot study were small (25/25) and the full results and demographic details will be reported under the full study results section. Each group (age/sex matched) consisted of 18 (72%) females and 7 (28%) males and the average age was over 75. When a three or six month period is specified it means three or six months preceding the interview (controls) or preceding admission (patient study group). Tables 4.1.0 and 4.1.1 show the number of life events occurring in the different groups.

Table 4.1.0 Total number of life events occurring in the preceding six months

	PATIENTS	CONTROLS	ALL
0-3 MONTHS	28	17	45
4-6 MONTHS	19	8	27
0-6 MONTHS	47	25	72

Tables 4.1.0 and 4.1.1 show that there was an excess of life events in the patient dementia group compared to the controls. In general, life events studies using the Brown and Harris (1978) method compare the number of individuals who have experienced one or more life events with marked or moderate threat within a specific



time period. In this study such an event will be referred to as 'severe'. The results of this study were then compared in this way as shown in Table 4.1.2.

Table 4.1.1 Total number of severe life events

	PATIENT	CONTROLS	ALL
0-3 MONTHS	22	13	35
4-6 MONTHS	15	3	18
0-6 MONTHS	37	16	53

The results of this small pilot study indicated that life events may be more frequent prior to admission/deterioration in this group of dementia patients compared with fit elderly controls. In particular the time period 4-6 months before admission seemed to be more important, suggesting that the life event may have preceded symptomatic deterioration rather than admission.

Table 4.1.2 Individuals with one or more severe life events

	Patients (total 25)	Controls (total 25)	Chi squared ( $\chi^2$ )	Probability
0-3 months	13	8	2.05	p < 0.25
4-6 months	12	3	7.72	p < 0.01
0-6 months	19	11	5.32	p < 0.05

It was notable that there was a large difference in life event rates for the fit elderly controls between the two time periods in that they experienced fewer in the 4-6 months period than in the first 3 months. With relatively small sample sizes this may be a chance finding; however, the full study should provide a clearer indication.

These results showed that the study was worth expanding to examine the effects of life events in more detail. In the larger study, life events could be examined with reference to a number of other criteria, including whether or not they could be construed as being independent of the subject's illness-related behaviour or part of the subject's capacity to precipitate them.

#### ***4.2.0 Measuring changes in routine and environment: reliability***

Reliability was assessed by three comparisons of the 30 observations that each rater made for each scale:

- Between the experienced rater (PB) and each of the naive raters.
- Between the two naive raters.

The results were subjected to a computer program for assessing inter-rater reliability using the weighted KAPPA statistical test (Cicchetti, 1976) which is widely acknowledged as suitable for assessing reliability between raters. This is because it is distribution-free and allows credit for partial agreement (Cohen, 1968; Hall, 1974).

The most important judgement was whether a life event implied any degree of change or not, rather than distinguishing between mild, moderate and severe change. Because

of this the distinction between 0 (no change) and 1 (mild change) was given a double weighting in the analysis. A KAPPA value of 0.8 or more is accepted as an excellent degree of reliability between raters (Landis and Koch, 1977). The results for environmental change and routine change are shown in tables 4.2.1 and 4.2.2.

**Table 4.2.1 : Environment change**

Comparisons	KAPPA	P
PB and NE	0.73	0.00001
PB and JO	0.86	0.00001
NE and JO	0.85	0.00001

Most of the results were above 0.8, and all were above 0.65. Good reliability was therefore obtained between both experienced and naive raters after brief training. Examination of the discrepancies between the raters suggest that they sometimes arose because the descriptions of some of the events were ambiguous.

**Table 4.2.2 : Routine change**

Comparisons	KAPPA	P
PB and NE	0.67	0.00002
PB and JO	0.81	0.00001
NE and JO	0.83	0.00001

Reliability is dependent on the clear specification of events and, with care, might therefore be further improved. In most cases, however, discrepancies were the result



of one of the raters failing to follow the guidelines correctly, despite adequate information. This suggests that reliability would also be improved by additional emphasis on following the guidelines during training.

#### ***4.3.0 Full study - selection process***

##### **Dementia patient group**

For the dementia patient group a total of 70 patients were needed. After speaking to the charge nurse and the junior doctors and after examining the admission register of the unit, all the patients who were potentially eligible for study were identified. At this stage the majority of the patients were excluded because the nurse or doctor provided information that made it obvious that the individual patient did not satisfy one or more of the inclusion criteria. At the next stage of selection the researcher went through the case notes carefully, to check more comprehensively if the patient fitted the criteria.

From the 94 patients entering this stage 10 were excluded on the grounds of diagnosis. Functional disorders excluded 2 (both paraphrenia) and the other 8 had a variety of organic disorders (2 tertiary syphilis, 3 alcoholic dementia, 2 delirium and 1 subdural haematoma). In addition, 4 patients were too physically unwell to be interviewed and 2 died before the interview could take place. Of the remaining 78 patients, 3 had remained in hospital outside the inclusion period, another 3 had no suitable informant, 1 patient had already been seen in another of the study groups and 1 relative refused to participate.

### **Fit control group**

For the fit elderly control group the initial selection process involved going through the age/ sex register of the Forest Hill Road General Practice and randomly selecting individuals of the same age and sex as the first 50 in the study group. After a group of individuals were selected, the list of names was discussed with one of the general practitioners (Dr Helen Graham) and the Practice Manager (Mrs Pat Claxton). At this stage people were excluded if they were known to suffer from recent psychiatric illness or a physical disorder likely to affect mental function (such as severe stroke). This procedure also enabled those patients who were known to have died recently to be excluded. In addition, patients who had recently participated in a study by Dr Graham were excluded at her request. This was unlikely to bias the result since the patients in Dr Graham's study had been randomly selected and did not form some other representative group. By this method, 78 patients needed to be selected, since of these 28 were excluded for various reasons, leaving the required 50 in the control group. Of the 28 excluded, 2 had died and 6 were ineligible on the grounds of diagnosis (at interview), 4 were found to have dementia, 1 had stroke and 1 had clinical depression. 4 others were found to have moved, while 5 were untraceable and had also presumably moved or left the area for a long period (e.g. one couple spent the summer in their caravan by the seaside). Of the 61 remaining 11 refused to participate and the other 50 were entered in the study. This means there was a total acceptance rate of 50/61 or 82% for participation the study. Many of the refusers wrote letters explaining their reasons for not wishing to participate. Four said they were unavailable or did not wish to participate, one said he was 'too busy' and two refused on the grounds of physical ill health (sciatica and blindness).



### **Dementia control group**

The dementia control group was drawn from two local day centres. Holmhurst Day Centre which was specifically for dementia sufferers, and the Evelyn Coyle Day Centre which was predominantly dementia sufferers but had a few clients who had some other form of long term mental illness. During the study period there were a total of 53 patients attending the two day centres and 28 on the waiting list. Since a total of 50 were required, the researcher began by working through those currently attending since more complete information was available on them. In this way, by the time the researcher was ready to interview those on the waiting list, some of those had already started attending and so also had more information available. It was also easier to contact and arrange to see relatives of clients who were already attending. Of the total 98 screened by discussion with the day centre manager and by examination of the medical and social notes, 10 were excluded because of diagnosis (3 affective disorder, 4 schizophrenia or paranoid psychosis, 2 stroke, 1 alcoholic dementia). 7 had been included on a previous occasion in another of the study groups. 3 died before they could be seen, 2 were currently in hospital, 2 had moved and 8 needed residential or nursing care within the next three months as they were no longer able to cope in the community. Of the remaining 65, 3 were excluded because they had a recent psychiatric admission, 1 was too young, 3 had no available informant, 1 was uncontactable and 1 refused. 50 were included in this control group and the remaining 4 (recent additions to the waiting lists) were not seen because they were not needed.



### ***4.3.1 Full study - demographics, health and social situation***

#### **Age**

Increasing age is associated with higher physical disability and may make it less likely that the person with dementia has a carer at home. This made it important to control as far as possible for age, which in turn improved the comparability of the groups. Since the 50 subjects in the fit elderly control group were selected using a case control method to match them for age and sex with the first 50 of the patient group, there should be little age difference between these groups when the full 70 in the patient group were compared. Table 4.3.1A shows the population in the three age groups. Because only two patients were under 65 (both 64) they have been incorporated into a 60-74 age group. The mean age of the dementia patients was 79.7 years, the dementia controls had a mean age of 78.0 years and the fit elderly controls had a mean age of 80.5 years. The t-test showed no significant differences in the ages of the three groups. However, age may be an important factor to take into account in other analyses as the dementia controls appear to have slightly more people in the younger age group.

Table 4.3.1A: Age groups

Age Groups	Patients	Dementia Controls	Fit Elderly	Total
60-74	10 (14.3%)	18 (36%)	8 (16%)	36 (21.2%)
75-84	44 (62.8%)	21 (42%)	27 (54%)	92 (54.1%)
85-98	16 (22.9%)	11 (22%)	15 (30%)	42 (24.7%)
ALL	70	50	50	170

## Sex

There was no significant difference between the sex ratios in each of the three groups as shown in Table 4.3.1B.  $\chi^2 = .423$ ,  $p = 0.8$ .

Table 4.3.1B: Groups by sex

	Patients	Dementia Controls	Fit Elderly	Total
Male	22 (31.4%)	17 (34%)	14 (28%)	53 (31.2%)
Female	48 (68.6%)	33 (66%)	36 (72%)	117 (68.8%)

## Education

There was no significant difference between the groups in terms of educational background (Table 4.3.1C). However, the fit elderly group had a higher proportion at the top educational level, and the dementia patient group had a slightly higher proportion of subjects with a below average education (achieved less than standard 7 at school) but this difference did not reach significance ( $\chi^2 = 0.45$ ,  $p > 0.05$ ).

Table 4.3.1C: Groups by education

	Dementia Patients	Dementia Controls	Fit Elderly	Total
Degree or diploma	4 (6%)	3 (6.3%)	9 (18%)	16 (9.7%)
Trade training	4 (6%)	3 (6.3%)	2 (4%)	9 (5.5%)
Standard 7	49 (73.1%)	37 (77.1%)	34 (68%)	120 (72.7%)
Less than Standard 7	10 (14.9%)	5 (10.4%)	5 (10%)	20 (12.1%)
ALL	67	48	50	165

## Social class

Social class was classified using standard tables (OPCS, 1981). In Table 4.3.1D the groups are shown by social class. The main finding is that there is a higher proportion of social class IV in both dementia groups and a significantly higher proportion of social class II in the fit elderly control group ( $\chi^2 = 8.63$ ,  $p < 0.05$ ). Since the social class breakdown for the two dementia groups is roughly the same this suggests that social class in itself does not predispose to admission for senile dementia sufferers.

Table 4.3.1D: Groups by Social Class

SOCIAL CLASS	Dementia Patients	Dementia Controls	Fit Elderly	Total
I	2 (2.9%)	3 (6.1%)	1 (2.0)	6 (3.6%)
II	9 (13.2%)	6 (12.2)	18 (36%)	33 (19.8%)
III	35 (51.5%)	21 (42.9%)	25 (50%)	81 (48.5%)
IV	17 (25%)	16 (32.7%)	5 (10%)	38 (22.8%)
V	5 (7.4%)	3 (6.1%)	1 (2%)	9 (5.4%)
TOTAL	68	49	50	167

## Psychiatric History

In the patient group, 6 (8.7%) subjects had parents and 6 (8.7%) had siblings with a history of dementia. In the dementia controls, 3 (6.5%) had parents and 9 had siblings with a history of dementia. In the fit controls there was no parental history and only 1 sibling history of dementia. There was a significant difference between the dementia groups compared to the fit elderly group in sibling history of dementia ( $\chi^2 = 8.58$ ,  $p < 0.05$ ) but not in parental history of dementia.



Four (5.8%) of the dementia patients, 1 (2.1%) dementia control and none of the fit controls had a history of a relative with alcohol problems. Eleven of the dementia patients, 5 (10.6%) of the dementia controls and 2 (4%) of the fit controls had a relative with other psychiatric problems.

Six (8.6%) of the dementia patients, 6 (12%) of the dementia controls and none of the fit controls had a previous admission of some sort because of dementia.

Nine (12.9%) of the dementia patients, only 1 (2%) of the dementia controls and 2 (4%) of the fit controls had a previous admission for some other form of psychiatric illness. However, the dementia patient group had a significantly higher rate of previous other psychiatric admission than the two control groups ( $\chi^2 = 6.25$ ,  $p < 0.05$ ). None of the subjects had a previous admission for alcohol problems.

### **Past medical history**

In terms of the past or current medical history each of the categories of illness was rated on a four point scale of severity using the following definitions.

**3) Severe** = Possibility of a real threat to life *and/or* resulting in severe disability or discomfort.

**2) Moderate** = Significant threat to physical wellbeing *and/or* resulting in moderate disability or discomfort.

**1) Mild** = No significant disability, mild discomfort *and/or* latent physical threat.

**0) No problems**

Tables 4.3.1E and 4.3.1F show the level of past and current physical illness in each of the three groups. In choosing the categories, particular attention was given to those groups of illnesses which would potentially affect the individual's mental state and cognitive function. There were no patients with any *current* problems rated as severe and this reflected the selection procedure which was specifically designed to exclude subjects with current severe physical illness that might affect their mental function and also designed so that the severe category covered disorders which caused severe disability or danger to life which might have made the individual more likely to be in a geriatric hospital bed with some physical disorder.

Table 4.3.1E: Past medical history - Numbers with mild/moderate/severe problems

Illness categories ->	Dementia Patients mild/mod/severe [ALL]	Dementia Controls	Fit Elderly
Cardiovascular	9 / 12 / 3 [24]	7 / 2 / 2 [11]	4 / 6 / 3 [13]
Respiratory	4 / 8 / 3 [15]	1 / 2 / 3 [6]	0 / 2 / 4 [6]
Neurological	4 / 6 / 1 [11]	4 / 5 / 0 [9]	2 / 6 / 3 [11]
Neoplasia	1 / 1 / 3 [5]	0 / 1 / 5 [6]	0 / 0 / 6 [6]
Metabolic/Endocrine	5 / 8 / 0 [13]	1 / 6 / 0 [7]	3 / 2 / 2 [7]
Infection	3 / 4 / 2 [9]	0 / 3 / 5 [8]	2 / 4 / 3 [9]
Orthopaedic	9 / 8 / 7 [24]	6 / 5 / 4 [15]	6 / 7 / 9 [22]

From the point of view of the cardiovascular system the dementia patients had a higher rate of past problems (in mild and moderate categories) compared to the other two groups. However, current cardiovascular problems were only higher for mild problems. This probably reflects the fact that a proportion of the dementia patients had mild physical problems as part of the overall deterioration leading to their admission.

There were no obvious differences for past or current problems in the neurological, neoplasia and infection categories. In general, neurological problems such as severe stroke would have been excluded by the selection procedure and there is no particular reason why differences might be expected in the other two categories.

Table 4.3.1F: Current medical history - Numbers with mild/moderate problems

Illness categories ->	Dementia Patients mild/moderate [ALL]	Dementia Controls	Fit Elderly
Cardiovascular	18 / 3 [21]	8 / 2 [10]	9 / 1 [10]
Respiratory	7 / 3 [10]	4 / 0 [4]	2 / 0 [2]
Neurological	4 / 1 [5]	6 / 2 [8]	5 / 4 [9]
Neoplasia	2 / 2 [4]	2 / 3 [5]	2 / 0 [2]
Metabolic/Endocrine	8 / 2 [10]	6 / 0 [6]	5 / 2 [7]
Infection	3 / 2 [5]	0 / 1 [1]	2 / 0 [2]
Orthopaedic	13 / 1 [14]	8 / 3 [11]	13 / 7 [20]

It is interesting to note that the dementia controls had a lower overall rate of current and past orthopaedic problems compared to both the other two groups. This may reflect a higher level of mobility in those people selected for the dementia day centres.

For the respiratory system the dementia patients had a higher rate of past moderate problems and a higher rate of current mild problems. In addition both groups of dementia subjects had a slightly higher rate of past metabolic or endocrine problems but this was not reflected in a higher rate of current problems.



It was also important to estimate the overall levels of past and current ill-health in the three groups. To do this, the physical problems in the moderate and severe categories were summated by allowing one point for a moderate problem and two points for a severe problem. The results are shown in Tables 4.3.1G and 4.3.1H. The  $\chi^2$  test was used to compare the scores for physical ill-health for each group and the tables were collapsed to provide adequate sample sizes.

Table 4.3.1G: Past physical ill-health

Ill-health scores	Dementia Patients	Dementia Controls	Fit Elderly
0 (well)	33 (47.1%)	23 (46%)	15 (30%)
1	14 (20.0%)	20 (10%)	9 (18%)
2	12 (17.1%)	16 (8%)	14 (28%)
3	4 (5.7%)	4 (8%)	3 (6%)
4	3 (4.3%)	2 (4%)	6 (12%)
5	4 (5.7%)	3 (6%)	3 (6%)

Although Table 4.3.1G shows that there was a lower proportion of people in the fit control group who had been previously well, there was no difference between the overall levels of past physical ill-health in the three groups ( $\chi^2 = 6.61$ , 6 df,  $p = 0.36$ ).

Table 4.3.1H: Current physical ill-health

Ill-health scores	Dementia Patients	Dementia Controls	Fit Elderly
0 (well)	52 (74.3%)	37 (74%)	37 (74%)
1	16 (22.9%)	10 (20%)	10 (20%)
2	2 (2.9%)	2 (4%)	1 (2%)
3	0	1 (2%)	2 (4%)

As shown in Table 4.3.1H, the rates of current physical ill-health were very similar in all three groups with only a quarter of individuals having current physical problems of moderate severity ( $\chi^2 = 0.00$ ,  $p = 0.99$ ). The results are also a count of the number of moderate problems each individual had (because there were no current severe physical problems in any of the three groups).

### **Physical disability**

Comparing the three groups, none of the fit elderly, 3 (4.3%) of the dementia patients and 8 (16%) of the dementia controls had a severe or extreme degree of recent physical disability. This suggests that deterioration in physical abilities was not an important factor contributing to a psychiatric admission compared to other factors (such as disturbed behaviour). It is therefore more likely that dementia sufferers with deteriorating physical abilities would be admitted to either nursing or residential homes or to a geriatric bed for assessment.

This is an important finding since this study looks at the effect of life events on deterioration and admission, thus a higher rate of physical dependency in the dementia patients group would make the results more difficult to interpret. The results may also indicate that some dementia day centres are able, or at least expected, to cope with a proportion of highly physically-dependent clients, such as people in wheelchairs and those requiring assistance walking or getting out of chairs.

Most subjects had only mild or no degree of physical dependency (fully mobile), including 58 (82.9%) of the dementia patients, 36 (72%) of the dementia controls and 39 (78%) of the fit elderly. These results suggest that the great majority of the dementia patients were no more or less physically dependent (in terms of mobility) than a comparable fit elderly population.

### **Sensory impairment**

This was assessed by informant interview using the questions on hearing and vision problems from the CAPE behavioral rating scale. Of the dementia patients 14 (20.3%) had vision problems compared to 9 (18.4%) of the dementia control group. Of the dementia patients 27 (39.1%) had hearing difficulties compared to 17 (34.7%) of the dementia control group. There were no significant differences between the dementia patient and dementia control groups.

### **Accommodation**

The sort of accommodation people lived in is shown in table 4.3.1I. Although the dementia groups did not have a higher proportion of people in sheltered accommodation, there was a significantly higher rate of council tenants compared to the fit elderly group ( $\chi^2$  14.23,  $p < 0.001$ ). In the fit elderly group the largest type of accommodation was owner-occupied followed by privately rented accommodation. This coincides with the group having a larger proportion of high social class (and hence possibly more affluent) subjects compared to the dementia groups.



**Table 4.3.1I Type of accommodation by group**

	Dementia Patients	Dementia Controls	Fit Elderly	Total
Owner occupied	18 (25.7%)	15 (30%)	20 (40%)	53
Private rented	5 (7.1%)	4 (8%)	12 (24%)	21
Council rented	29 (41.4%)	27 (54%)	9 (18%)	66
Sheltered flat	8 (11.4%)	4 (8%)	9 (18%)	21
Residential home	8 (11.4%)	0	0	8
Other	2 (2.9%)	0	0	2
Total	70	50	50	170

#### Structural condition of accommodation

This rating was meant to assess structural problems such as dry rot, ceilings down, subsidence etc and not superficial decoration/cleanliness. None of the accommodation was rated as severely structurally dilapidated (4 or more on the scale of 0 to 5), and only 7 (10%) of the dementia patients, 5 (10%) of the dementia controls and 6 (12%) of the fit elderly groups lived in accommodation scoring a rating of 1 (very mild problems with structural condition) or more. These results suggest that, in terms of the fabric of the building, there was no difference between the accommodation of the three groups; in particular the dementia sufferers were not in fundamentally poorer accommodation than the fit elderly.

#### Superficial condition of accommodation

This rating was intended to reflect the overall state of decoration and cleanliness of the accommodation. None of the accommodation was rated as 'extremely dirty/neglected' (score 5) although 1 dementia patient had a rating of 'severely dirty/neglected' (score

4) for their accommodation and another had a moderate (3) rating on this scale. Overall 11 (15.7%) dementia patients, 7 (14%) dementia controls and 3 (6%) of fit elderly had accommodation rated as 1 or 2 (very mild or mild). The most likely explanation for the slightly higher proportion of cleanliness/decoration problems in the accommodation of dementia sufferers is that in the course of the dementia's progress they lose the capacity to do cleaning activities. Even so it is perhaps surprising that a higher proportion of dementia sufferers didn't have some problems in this respect, so it may indicate that relatives or home helps are generally managing to keep things reasonably clean and tidy

### **Support services**

Support services were divided into *professional* (community psychiatric nurse (CPN), district nurse, social worker), *other statutory* (meals on wheels, home help), *voluntary worker, relatives* and *other* (for everything else such as input from friends/neighbours). These were classified on a scale of 0 to 4 to indicate the degree of support provided where 0 = no involvement, 1 = contact only, 2 = minor degree of support (usually one to two times per week), major degree of support (usually three to four times weekly), full support (daily input). For the dementia patients group the involvement of such help was rated for the period before admission and therefore did not include individuals who had acquired help (e.g. CPN or social worker) afterwards.

### **Community psychiatric nurse (CPN)**

Six (12%) of the dementia controls and 4 (5.7%) of the dementia patients had a CPN, but none of the fit elderly did. Only 1 dementia sufferer had a CPN providing 'full'



or 'major' support and as this individual was from the patient group it may be that he or she received particularly high support in order to try and prevent admission.

#### District nurse

Nine (13.1%) of the dementia patients, 15 (30%) of the dementia controls, and 2 (4%) of the fit elderly had district nurse input. In particular 9 (18%) of the dementia controls had 'major' or 'full' input, compared to only 3 (4.3%) of the dementia patients and none of the fit elderly. This suggests that for a specific group of dementia patients it may be possible to get intensive district nurse help, and that this is significantly more likely when a day centre is also involved in the care package ( $\chi^2 = 13.59$ ,  $p < 0.005$ ).

#### Social work

Twenty-two (31.4%) of the patients, 8 (16%) of the dementia controls, but none of the fit elderly had a social worker. There was a highly significant association between the diagnosis of dementia and the involvement of a social worker ( $\chi^2 19.96$ ,  $p < 0.0001$ ). There was also an association between the degree of involvement and admission for dementia compared to the community dementia group ( $\chi^2 = 8.79$ ,  $p < 0.005$ ). The lower rate of involvement for the dementia control group probably reflects the fact that they were less likely (by definition) to be in a stage of deterioration which would lead to the involvement of professionals, and they were already considerably supported by the day centres. Many of this group may have had social workers in the past but had been discharged from their case load because they were stable and/or sufficiently well supported by the day centre. This finding also suggests that social workers were more



likely to be involved in acute situations when they were needed to try to forestall or facilitate admission as appropriate.

### Meals on wheels

Only 2 (4%) of the fit controls had meals on wheels compared to 11 (22%) of the dementia controls and 16 (22.9%) of the dementia patients. The dementia groups were significantly more likely to receive meals on wheels ( $\chi^2 = 8.55$ ,  $p < 0.05$ ). Most people who received meals on wheels (26 of 29) had them three to five times per week. This finding obviously reflects the fact that people with dementia are less well able to prepare an adequate diet for themselves, but the figures do not provide an estimate for the proportion of dementia sufferers unable to do so since many people are looked after and catered for by their relatives. In addition, many of the dementia controls were receiving at least one and mostly three or more midday meals per week from the day centres on the days they attended.

### Home help

Twenty-three (32.9%) of the dementia patients, 19 (38%) of the dementia controls and 12 (24%) of the fit elderly received some degree of home help. 'Major' or 'full' support was received by 15 (21.5%) of the dementia patients, 15 (30%) of the dementia controls, but only 3 (6%) of the fit elderly received major or full home help. Thus, both of the groups with dementia had home help more frequently than the fit elderly group and this was also more intensive ( $\chi^2 = 9.51$ ,  $p < 0.01$ ). A slightly higher proportion of the dementia controls received major or full support compared to the dementia patients ( $\chi^2 = 0.73$ ,  $p > 0.25$ ). This may reflect the fact that they were

already being supported by the system to some extent since they were all attending day centres; whereas the patient group were sometimes newly-presenting without any involvement of health or social services.

### Day centre

Of the fit elderly group 3 (6%) attended a day centre (which by definition would not be one for dementia sufferers), 12 (17.1%) of the dementia patients and 37 (74%) of the dementia controls attended a day centre. The latter figure was not 100% because 13 of the dementia controls were on the waiting list of one of the two day centres. There was usually a wait of one to six months before commencing attendance.

### Voluntary help

Only one person received voluntary help and he was from the dementia control group. This is a surprisingly low figure but may not reflect the support given directly to carers since both dementia day centres ran carer support groups.

### Support from relatives

35 (70%) of the dementia controls, 34 (48.6%) of the dementia patients, and 5 (10%) of the fit elderly had *full* (daily) support from relatives (usually the spouse). By contrast, 23 (46%) of the fit elderly, 10 (14.3%) of the dementia patients and only 4 (8%) of the dementia controls had no contact or support from relatives. This is not a surprising finding since dementia day centres are better able to support dementia patients in the community where relatives are also involved, and many relatives find

that they need to provide regular help in order to try and maintain the dementia sufferer at home.

#### Other support

35 (70%) of the fit elderly, 36 (72%) of the dementia controls and 49 (70%) of the dementia patients had no other forms of contact or support. 9 (18%) of the dementia controls and 11 (15.7%) of the dementia patients, compared to 2 (4%) of the fit elderly, had major or full support classified as other. This was generally provided by friends or neighbours, and the results suggest that, although dementia sufferers are no more likely than fit elderly to have this form of support, where other such support is involved it is quite often fairly intensive.

#### **Informants**

By definition, in terms of the entry criteria, all subjects with dementia had to have a suitable informant in order to be eligible for the study. A sample of the fit elderly also had an informant who was interviewed, in order to compare the reporting of life events by an informant. To an extent this depended on who was available for interview, but in practice 16 of the 50 (32%) fit elderly had an informant. The breakdown of who the informants were is shown for each group in table 4.3.1J. In each dementia group, daughters were the most frequent informants, followed by spouses. It is notable that the dementia patient group had a higher proportion of sons (18.6%) as informants, compared to the dementia controls (8.0%) who had a higher proportion of daughters (42% against 24.3%), although these differences did not reach significance ( $p > 0.05$ ).



It may be a chance finding, or suggest that sons were less likely to be able to recruit help from day centres for looking after their relative.

Table 4.3.1J Informants by group

	Dementia Patients	Dementia Controls	Fit Elderly
Spouse	13 (18.6%)	16 (32%)	9 (18%)
Daughter	17 (24.3%)	21 (42%)	1 (2%)
Son	13 (18.6%)	4 (8%)	0
Sister or brother	7 (10%)	5 (10%)	1 (2%)
Other relative	9 (12.9%)	1 (2%)	2 (4%)
Friend/other	11 (15.8%)	3 (6%)	3 (6%)
TOTAL	70 (100%)	50 (100%)	16 (32%)

### Cohabitees

Table 4.3.1K shows the cohabitees for the subjects in each group. A similar proportion in each group lived alone, suggesting that living alone in itself may not be a predisposing factor to hospital admission ( $\chi^2 = 1.68$ ,  $p > 0.25$ ).

Table 4.3.1K Cohabitees by group

	Dementia Patients	Dementia Controls	Fit Elderly
Spouse only	15 (21.4%)	14 (28%)	12 (24%)
Other relative only	3 (4.3%)	7 (14%)	1 (2%)
Two or more relatives	11 (15.7%)	5 (10%)	5 (10%)
Friend	2 (2.9%)	1 (2%)	3 (6%)
Alone	39 (55.7%)	23 (46%)	29 (58%)
TOTAL	70	50	50

There were no obvious differences between the groups in terms of who the cohabiters were, but there was a higher proportion of dementia controls who lived with one relative compared to dementia patients. Conversely, more dementia patients lived on their own, or with two or more relatives, compared to the dementia controls.

### **Social contacts**

The average number of daily contacts was calculated for each of the subjects. Initially this was divided into weekday and weekend contacts, and a total number of weekly contacts was also calculated. For individuals living alone, weekends were often the most isolated time. Table 4.3.1L shows the average frequency of daily social contact. The results are obviously heavily biased by the fact that most of the community dementia controls were already attending day centres up to six times per week, which means that all of these people would score five contacts a day for each day attended. This is because in rating the number of contacts, each day centre attendance was counted as five contacts and the maximum of eight daily contacts usually occurred when there was a cohabitee.

**Table 4.3.1L Average number of social contacts per day by group**

	Dementia Patients	Dementia Controls	Fit Elderly
Less than 1	4 (5.8%)	1 (2%)	5 (10%)
1 to 3	15 (21.7%)	3 (6%)	19 (38%)
4 to 7	7 (10.1%)	20 (40%)	3 (6%)
8 or more	43 (62.3%)	26 (52%)	23 (46%)
Total	69	50	50

The dementia controls had significantly more frequent social contact than either the dementia patients ( $\chi^2 = 5.90$ ,  $p < 0.05$ ) or the fit elderly ( $\chi^2 = 17.91$ ,  $p < 0.00$ ). However, it is interesting to note that the dementia patients also had a significantly higher frequency of social contact than the fit elderly ( $\chi^2 = 4.41$ ,  $p < 0.05$ ). This may suggest that isolation in itself is not necessarily a predisposing factor in acute deterioration of dementia sufferers since they actually appeared to be less isolated than the age/sex matched comparison control group.

### **Quality of relationship with carer**

When they lived in the same residence, the quality of relationship between the carer and subject was looked at using three scales (Bergmann et al., 1984) (see appendix 7.1.3 for full definitions):

- 1) Dominance versus Submissiveness
- 2) Negative versus Positive communication
- 3) Physical dependency versus Independence

The ratings were made by reference to the notes, discussion with staff and interview with the key relative (informant). Ratings were on a seven point scale. This section was not completed for the fit elderly group because it was not relevant and there was also a lack of informants, psychiatric or social work notes, and staff reports, so that it could not have been adequately completed. Table 4.3.1M shows that there appeared to be a tendency for relatives in the dementia patients group to appear less in control of the interactions with the individual, although this difference was not significant.



**Table 4.3.1M Dominance and submissiveness in relationship between key relative and dementia sufferer**

Dominance vs Submissiveness	Dementia Patients	Dementia Controls
Patient mainly in control	8 (22.2%)	4 (14.8%)
Equal sharing of power	8 (22.2%)	3 (11.1%)
Relative mainly in control	20 (55.5%)	20 (74.1%)
Total	36	27

In Table 4.3.1N there appears to be more of a difference, in that there is a lower level of positive communication in the dementia patient group and the difference reaches the  $p < 0.05$  significance level ( $\chi^2 = 5.31$ ). It is not possible to know what the results would be for those relatives/carers who were looking after dementia sufferers in the community without additional day centre support, so it is difficult to draw particular conclusions from these results. Having said that, the results might suggest that a high level of conflict in the relationship with the key relative, or the relative lacking a feeling of control in the relationship, may be risk factors in the process of acute deterioration and presentation to services for the dementia sufferer. But considering the numbers involved, these variables may only be risk factors for the minority.

The dementia control group appeared to be no less physically dependent (in terms of basic care in washing, dressing, feeding etc.) than the dementia patient group. The controls had 18 out of 27 (55%) individuals requiring maximum care compared to 20 out of 35 (57.2%) for the dementia patients.

This suggests that physical dependency in itself is not a risk factor influencing admission, or that relatives are able to cope with a higher degree of physical dependency in the community, if they have sufficient support.

**Table 4.3.1N Negative communication in relationship between key relative and dementia sufferer**

Conflict in communication	Dementia Patients	Dementia Controls
Mainly negative communication	9 (25%)	2 (7.4)
Equal negative and positive communication	9 (25%)	3 (11.1%)
Mainly positive communication	18 (50%)	22 (81.5%)
Total	36	27

### **Multivariate analysis of supportive resources**

In order to see which types of supportive resources discriminated between the two dementia groups when other factors were taken into account, a logistic regression analysis was performed using the likelihood ratio (LR) method, with group membership as the dependent variable. The other variables entered were those which appeared to differ between the two dementia groups, namely: social contacts, support from relatives, social work, district nursing, and home help. The results are shown in Table 4.3.1O.

**Table 4.3.1O Logistic regression analysis comparing supportive resources of the two dementia groups.**

----- Model if Term Removed -----				
<u>Term</u>	<u>Log</u>	<u>Significance</u>		
<u>Removed</u>	<u>Likelihood</u>	<u>-2 Log LR</u>	<u>df</u>	<u>of Log LR (p)</u>
Support from Relatives	-72.50	3.18	1	.0745
Social Work	-74.97	8.12	1	.0044
District Nursing	-74.69	7.56	1	.0060

Table 4.3.1O shows that dementia patients had significantly more social work, but less district nursing than the dementia controls. In addition, there was a trend for the dementia patients to have less support from relatives.

In a further analysis, two of the variables assessing quality of relationship were also included. This was restricted to those subjects who had a carer as a cohabitee and therefore only included 36 dementia patients and 27 dementia controls. The final model produced by the stepwise logistic regression correctly classified 71% of all dementia subjects and included three variables: support from relatives (-2 log LR = 4.51,  $p < 0.05$ ), district nursing (-2 Log LR = 4.72,  $p = 0.03$ ) and negative communication (-2 Log LR = 6.90,  $p = 0.01$ ). The dementia patients had less support from relatives, and district nursing input, and had more problems of negative communication in the relationship with their carer.



### ***4.3.2 Psychiatric symptoms, mental state and behavioural ratings***

#### **Diagnosis**

In classifying the groups, consultant clinical diagnosis was used, corroborated by an assessment of the case notes, informant history, brief cognitive test (usually the Mini Mental State Examination as completed by the ward doctor) and the Geriatric Mental State Schedule (validated diagnostic interview which includes a cognitive scale). Thus in order to receive a diagnosis of dementia and be included in the study, the results of the various stages above needed to be compatible with such a diagnosis (and to fulfil the other inclusion criteria).

The dementia category was based on the consultant diagnosis and on reference to the medical notes and other medical staff involved. As previously stated, only primary degenerative dementias were included. The proportions of various subcategories of dementia are shown in Table 4.3.2A and are broadly in line with the expected proportions of degenerative dementias in the community (Lishman, 1987).

Table 4.3.2A Classification of dementia

	Dementia Patients	Dementia Controls	Total
Alzheimer's disease	54 (77.1%)	38 (76%)	92 (76.7%)
Multi-infarct (MID)	8 (11.4%)	10 (20%)	18 (15%)
Mixed (Alzheimer's and MID)	6 (8.6%)	1 (2.0%)	7 (5.8%)
Other	2 (2.9%)	1 (2%)	3 (2.5%)
TOTAL	70	50	120

The types of dementia classified under 'other' included 1 frontal lobe dementia and 1 Binswanger's Disease in the patient group and 1 Parkinson's disease dementia in the control group. There was absolutely no difference between the two groups when comparing Alzheimer's disease with the other dementias ( $\chi^2 = 0.01$ ,  $p = 0.94$ ).

### **Duration of illness**

The date of onset of illness was elicited by asking the informant about the earliest time that they noticed any signs that the dementia sufferer was beginning to have mental symptoms attributable to possible cognitive decline. Commonly these included: loss of interest in activities (such as reading), losing things, forgetting important dates and forgetting to pay bills.

The dementia patients had a mean duration of illness of 40.7 months (3.4 years) which was much shorter than the mean duration of illness of the dementia controls of 65.4 months (5.4 years). This was a highly significant difference ( $t = -3.09$ ,  $p = 0.002$ ) which probably reflects the fact that it often takes some time between diagnosis, referral, and the offer of a dementia day centre place.

### **Severity of dementia**

The severity of the dementia by group is shown in Table 4.3.2B. This has been compiled using the AGE CAT computer program to analyse the GMSS data into an index of severity on a scale of 0 to 5. Scores of 2 or less have been classified as mild, 3 as moderate, 4 as severe and 5 as very severe. There was no difference in the degree

of severity between the patients and controls ( $\chi^2 = 1.84$ ,  $p = 0.40$ ). The admitted group, however, had a slightly higher proportion of both mild and of severe cases.

Table 4.3.2B Severity of dementia - cognitive impairment

	Dementia Patients	Dementia Controls	Total
Mild	11 (15.7%)	6 (12%)	17 (14.2%)
Moderate	25 (35.7%)	24 (48%)	49 (40.8%)
Severe	27 (38.6%)	17 (34%)	44 (36.7%)
Very severe	7 (10%)	3 (6%)	10 (8.3%)
TOTAL	70	50	120

### Other psychiatric symptoms

Using the GMSS-AGECAT system it was possible to assess the levels of a range of psychiatric symptoms. The drawbacks of such an approach are that only an immediate picture of the symptomatology is possible. Since dementia patients may have intermittent symptoms such as paranoid ideas or hallucinations, they may not remember them at interview, and so this method may underestimate psychopathology when compared with studies which look at the entire period of the illness (Burns et al., 1990).

Table 4.3.2C shows the frequency of other psychiatric symptoms occurring, without reference to their severity. The great majority of symptoms fell into one of the mild categories (GMSS scale score 1-2). One of the dementia patients scored as severe for the 'Mania - Elated' category and also scored as severe in terms of cognitive impairment and dementia. One of the dementia patients scored as severe for depressive



symptoms, and 5 dementia patients, 5 dementia controls and 2 fit elderly scored as moderate for depressive symptoms. One dementia patient and 4 fit elderly scored as moderate for hypochondriacal symptoms, but this result may possibly reflect true physical symptoms in the fit elderly which the investigator did not detect (perhaps because a physical examination was not part of the assessment).

Table 4.3.2C Other psychiatric symptoms by group

CATEGORIES OF SYMPTOMS	Dementia Patients	Dementia Controls	Fit Elderly
Schizophrenic/paranoid	2 (2.9%)	4 (8%)	0
Manic	2 (2.9%)	0	0
Depressive	13 (19%)	13 (26%)	8 (16%)
Obsessional	0	2 (4%)	0
Hypochondriacal	1 (1.4%)	0	5 (10%)
Phobic	1 (1.4%)	1 (2%)	3 (6%)
Anxiety	20 (28.6%)	16 (32%)	10 (20%)

One dementia patient scored as severe for anxiety, and 1 dementia patient and 1 fit elderly scored as moderate for anxiety. All but 3 dementia subjects who had moderate levels of other symptoms had at least moderate or severe cognitive impairment, suggesting that the dementia was in any case the primary diagnosis.

### **Behavioural symptoms**

Using the CAPE behavioural rating, the current levels of behaviour problems and of dependency could be assessed using the overall total score and the four subscores.

Each of the questions was scored from 0 to 2, 0 indicating no difficulties, 1 some difficulties and 2 significant difficulties in each area. Table 4.3.2D shows the proportion of subjects in each group who have some degree of difficulty in each of the areas.

Table 4.3.2D CAPE behaviour rating scale items; the number of subjects with some degree of difficulty in each of the 18 categories.

	Dementia Patients	Dementia Controls
1. Problems dressing or bathing	52 (74.3%)	33 (66%)
2. Difficulty walking	34 (48.6%)	21 (42%)
3. Incontinence (p < 0.01)	32 (45.7%)	14 (28%)
4. Stays in bed during day	16 (22.8%)	18 (36%)
5. Confused / loses things	64 (91.4%)	46 (92%)
6. Disorderly appearance	56 (80%)	41 (82%)
7. Needs supervision outside	64 (91.4%)	43 (86%)
8. Doesn't help out	54 (77.1%)	31 (62%)
9. Inactivity	59 (84.3%)	41 (92%)
10. Social difficulties	21 (44.3%)	16 (32%)
11. Uncooperative	36 (52.2%)	29 (58%)
12. Understands little	24 (34.3%)	17 (34%)
13. Difficult to understand them	29 (41.4%)	19 (38%)
14. Objectionable behaviour during day	27 (38.6%)	14 (28%)
15. Objectionable behaviour at night (p < 0.05)	20 (28.6%)	5 (10%)
16. Suspicious	23 (22.9%)	20 (40%)
17. Hoarding (p < 0.05)	21 (30%)	25 (50%)
18. Sleeping problems	28 (40%)	16 (32%)

As is shown, for 15 of the variables there was little difference between the two groups. However, the patient groups were significantly more likely to be incontinent ( $\chi^2 = 9.60, p < 0.01$ ), and have more disturbed behaviour at night ( $\chi^2 6.13, p < 0.05$ ). These two problems are ones which often cause a high degree of distress to relatives. For some reason, the control group were more likely to hoard things than the patient group ( $\chi^2 = 6.13, p < 0.05$ ). Although these results are interesting, the large number of comparisons means that some of the significant findings could have occurred by chance rather than real association.

#### **Behavioural symptoms: CAPE subscores and total**

The means for each subscore and the full CAPE score are shown in table 4.3.2E. The proportion of subjects in each of the dependency groups using the full CAPE score is shown in Table 4.3.2E.

The subscores and overall CAPE score were compiled by adding the appropriate individual scores (see above). This gave a maximum on the full CAPE of 36 (indicating maximum dependency) and on each of the subscores as below.

- 1) physical disability (items 1-6) MAXIMUM 12
- 2) apathy (items 7-11) MAXIMUM 10
- 3) communication difficulties (items 12-13) MAXIMUM 4
- 4) social disturbance (items 14-18) MAXIMUM 10



**Table 4.3.2E CAPE behavioural scale dependency categories by group**

Dependency level and scores	Dementia Patients	Dementia Controls
No impairment: (0-3) INDEPENDENT	2 (2.9%)	1 (2%)
Mild impairment: (4-7) LOW DEPENDENCY	9 (13%)	5 (10.2%)
Moderate impairment: (8-12) MEDIUM DEPENDENCY	15 (21.7%)	16 (32.7%)
Marked impairment: (13-17) HIGH DEPENDENCY	25 (36.2%)	15 (30.6%)
Severe impairment: (18+) MAXIMUM DEPENDENCY	18 (26.1%)	12 (24.5%)
TOTAL	69	49

To assess any relationship between the CAPE score and the two groups, t-tests were performed on the total CAPE score and each of the four subscales, as shown in Table 4.3.2F. The results show no differences in the overall CAPE score or subscores between the two groups; in fact the means all look strikingly similar, suggesting that in terms of current dependency levels they are comparable.

**Table 4.3.2F CAPE behavioural scores: means and t-test comparing groups**

	Mean Patients	Mean Controls	t value	probability
1) physical disability	5.51	5.62	-0.25	0.83
2) apathy	5.35	5.08	0.61	0.54
3) communication difficulties	0.91	0.84	0.35	0.73
4) social disturbance	2.31	2.32	-0.01	0.99
5) Full CAPE behavioural	14.20	13.92	0.25	0.80

The CAPE is recognised as an instrument which can predict levels of care needed and outcome (Pattie and Gilleard, 1979). It would seem, therefore, that the hospital group are likely to have a similar course and prognosis to the control group, if the other factors such as carer support and services are not considered.

### **Assessment of acute deterioration**

In order to look at the process of acute deterioration prior to admission in more detail, aspects of the subject's behaviour and mental state were rated in terms of how they had worsened over the past six months using the informant interview, discussion with staff involved and reference to medical and social case notes. Each variable was rated on a four point scale where 0 = no deterioration, 1 = mild deterioration, 2 = moderate deterioration and 3 = severe deterioration. The 'other' category included whatever additional symptoms the informant felt relevant (e.g. hallucinations, falls, misidentification problems etc.).

Table 4.3.2G shows the proportion of subjects in each group who were reported to have become worse in each of the symptom groups. As expected, all the scores are higher in the patient group with the exception of depressive/withdrawn symptoms. This is a new measure and as such its value is not established. However a reliability study comparing two raters using the measure and also evaluating the need for some form of admission is reported in section 4.4.0.

**Table 4.3.2G Subjects with scores indicating acute deterioration in the symptom groups**

CATEGORIES OF SYMPTOMS	Dementia Patients	Dementia Controls	$\chi^2$	p
Irritable/suspicious	37 (53.9%)	16 (32%)	8.44	< 0.05
Depressive/withdrawn	21 (30%)	16 (32%)	0.00	(0.97)
Restless/wandering	44 (62.9%)	12 (24%)	23.65	< 0.000
Aggressive/disinhibited	25 (36.2%)	8 (16%)	4.74	< 0.05
Cognition	69 (98.6%)	34 (68%)	23.77	< 0.000
Self-care problems	46 (65.7%)	20 (40%)	8.58	< 0.05
Sleep disturbance	39 (56.5%)	5 (10%)	27.98	< 0.000
Incontinence	21 (30.4%)	7 (14%)	3.49	(0.06)
TOTAL	70	50		

In accord with the CAPE results, disturbed behaviour, particularly at night, appears to increase the risk of admission. Looking at the deterioration scores by group in Table 4.3.2H it is evident that while none of patients fell into the mild deterioration category, more than half the controls (56%) did. This suggests that the score does indeed provide an index of deterioration, in that the control group were chosen to be relatively stable and not in imminent danger of breakdown and admission to hospital or a nursing or residential home. In addition, none of the subjects scored more than 20 even though the maximum possible score was 27. Comparing the means for acute deterioration, the dementia controls had a mean of 5.2 whereas the dementia patients had a mean of 10.0, nearly 5 points higher ( $t = 7.36$ ,  $p < 0.01$ ). A higher acute deterioration score may have value in predicting admission. Indeed, these results suggest that the deterioration score may even be more useful than the CAPE for this purpose, although it is so far otherwise untested. Further results looking at the acute



deterioration score as a predictor of admission and prognosis are reported in sections 4.4.0 and 4.5.1.

Table 4.3.2H Acute deterioration scores by group

Acute deterioration score	Dementia Patients	Dementia Controls
MILD: 0 to 5	0	28 (56%)
MODERATE: 6 to 10	39 (57.4%)	17 (34%)
SEVERE: 11 to 15	26 (38.2%)	3 (6%)
VERY SEVERE: 16 to 20	3 (4.4%)	2 (4%)
TOTAL	68	50

Since only a proportion of dementia patients had a datable deterioration (43 of 70), it was important to know if having an identifiable date for deterioration related to behavioural dependency and severity of acute deterioration. With this in mind, t-tests were performed comparing the subgroups of dementia patients with and without a specified date for deterioration, on their CAPE and acute deterioration scores. There were no significant differences between the groups for level of deterioration ( $t = -0.44$ ,  $p = 0.66$ ) or total CAPE score ( $t = -1.76$ ,  $p = 0.08$ ). However, there was a trend for those with a date for acute deterioration to have higher dependency.

It was considered possible that the CAPE and acute deterioration results might differ according to whether the dementia sufferer lives alone or with a cohabitee who is exposed to the deteriorating behaviour, worsening cognition and possibly an irritable or suspicious mood. With this in mind a logistic regression analysis was carried out looking at presence or absence of cohabitee as the dependent variable in the two

dementia groups. The independent variables (in addition to the dementia group) included the CAPE and Acute deterioration scores and individual behaviours which might be particularly distressing to cohabiters (wandering, irritability/suspiciousness, objectionable behaviour at night, and cognitive impairment). Only the occurrence of objectionable behaviour at night ( $-2 \text{ Log LR} = 5.83$ , 1 df,  $p = 0.016$ ) was significantly associated with the presence of a cohabitee when the effects of the other factors were taken into account.

### ***4.3.3 Life events preceding admission***

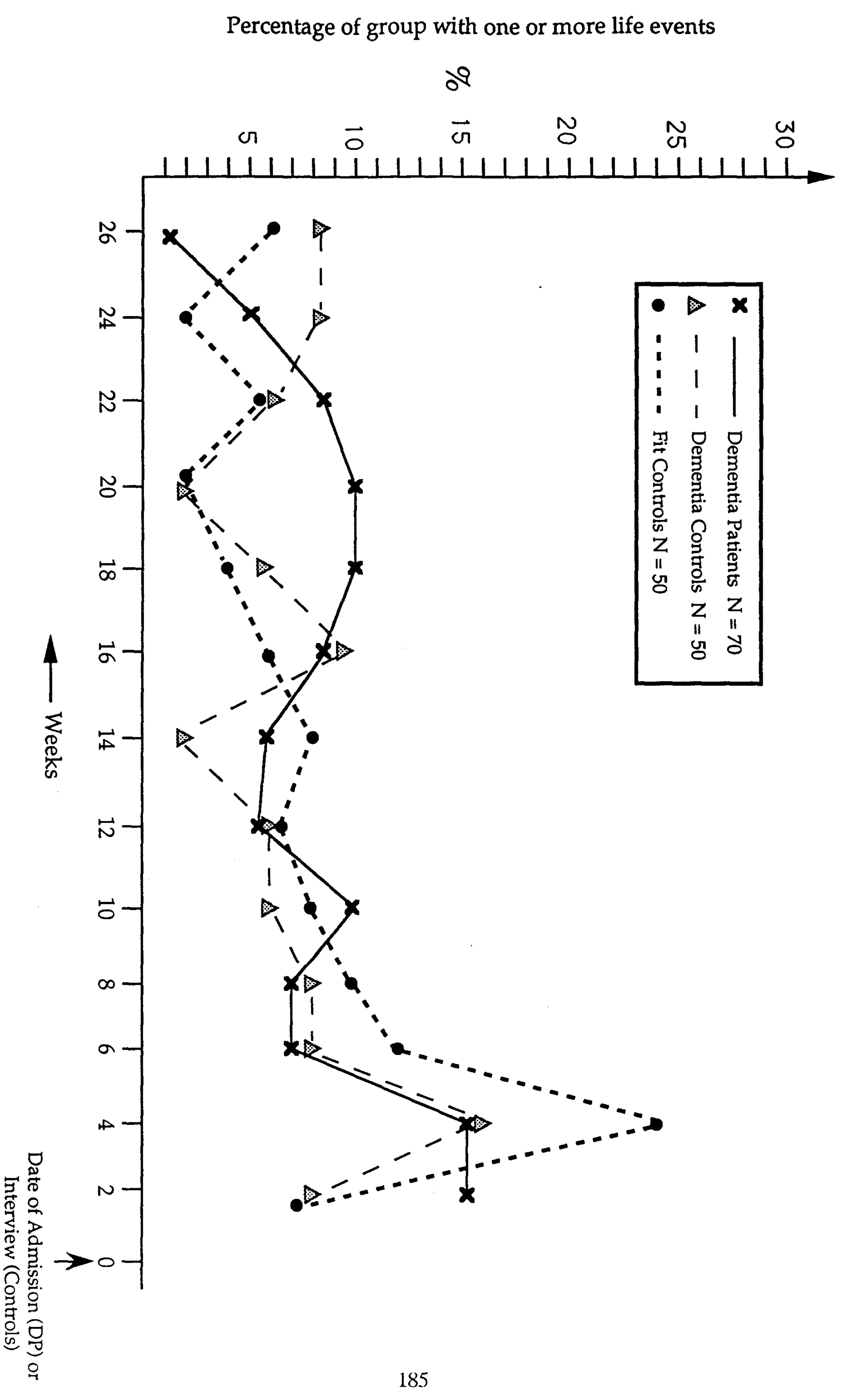
This section (and the following section, 4.3.4) examines the relationship between life events and admission (or acute deterioration) in senile dementia sufferers. In particular, it addresses the emotionally stressful qualities of life events, to see if the more threatening events are more likely to be associated with admission or deterioration. It also examines whether any link is merely the result of life events which the individual could have precipitated in the course of a deterioration leading to an admission.

As a preliminary to more detailed analysis, the patterns of life event experience are displayed graphically in Figure 4.3.3. This shows the percentage of subjects from each group who had experienced a life event of any kind in the six months before the date of admission (dementia patients) or of interview (dementia controls and fit elderly controls).

Overall, there appears to be little difference between the two control groups and the dementia patients group in the period of time from eight to 26 weeks before the key date (admission or interview). The three principle groups all show a peak in the proportion of subjects experiencing life events in the four weeks before the key date, and this peak is actually most notable in the fit elderly controls. The reasons for the similarity of these patterns are unclear, and the excess of life events at this time for the fit elderly (of whom 24% had experienced a life event) was unexpected. However, two weeks before the date of admission, the dementia patients had an excess of life events compared to the two control groups.



**Figure 4.3.3** Percentage of subjects in each group with one or more life events in the previous six months.



Comparisons were made for the total number of life events per subject in the six month period before admission for the dementia patients group and the six month period before interview for the two control groups, as shown in Table 4.3.3A. It does not take into account the severity of events or whether they could be construed as independent of the subject's own actions. As can be seen from this superficial analysis, the three groups seem quite similar: roughly a third of each had no life events, a third had one, and a third had two or more events. Predictably, there is no significant difference in the number of such life events per subject between any of the three groups ( $\chi^2 = 0.68$ ,  $p > 0.5$ ).

Table 4.3.3A Total life events in the three groups in the six months before admission (or interview for controls)

Number of Life Events	Dementia Patients	Dementia Controls	Fit Elderly
None	24 (34.3%)	18 (36%)	19 (38%)
One	24 (34.3%)	19 (38%)	16 (32%)
Two	14 (20%)	9 (18%)	9 (18%)
Three	3 (4.3%)	3 (6%)	6 (12%)
Four	2 (2.9%)	1 (2%)	0
Five	1 (1.4%)	0	0
Six	2 (2.9%)	0	0
Total life events	86	54	46
Total subjects	70	50	50
Life events per subject	1.23	1.08	0.92

### Severe life events in the six months preceding admission

Studies using Brown and Harris's (1978) schedule generally infer that individuals are significantly exposed to stress if they have one or more life events of marked or moderate threat in the given time period. Unlike Brown and Harris the question of the focus of the life event was not addressed in rating the severity. This was because of the literature suggesting that individuals with dementia are very sensitive to stress and the use of only events focused on the individual, was thought to be too parsimonious. Therefore, all events of marked or moderate threat will be denoted '*severe*' life events in all parts of the results. Hence, for the purposes of this stage of the analysis only severe events were included and individuals were classified by whether or not they had one in the preceding period as shown in Table 4.3.3B.

Table 4.3.3B Number of subjects with at least one severe threat life event before admission

TIME PERIOD	Dementia Patients	Dementia Controls	Fit Elderly
0-4 weeks	15 (21.4%)	5 (10%)	11 (22%)
5-8 weeks	10 (14.3%)	5 (10%)	10 (20%)
9-12 weeks	9 (12.9%)	3 (6%)	5 (10%)
13-16 weeks	9 (12.9%)	5 (10%)	5 (10%)
17-20 weeks	9 (12.9%)	4 (8%)	3 (6%)
21-26 weeks	8 (11.4%)	6 (12%)	4 (8%)
0-3 months	27 (38.6%)	12 (24%)	18 (36%)
4-6 months	21 (30%)	13 (26%)	10 (20%)
0-6 months	38 (54.3%)	21 (42%)	21 (42%)



As Table 4.3.3B shows, there were no obvious differences between the patient group and either of the two control groups. None of the differences between the groups reach the standard  $P < 0.05$  significance level and most  $P$  values exceeded 0.25. The only notable feature in Table 4.3.3B is that the patient group does have a slightly increased rate of life events over the two control groups in many of the comparisons, but the importance of this finding is uncertain. If this was a true difference it was not very large and would obviously require much bigger groups to achieve significance levels.

#### **Severe and independent life events in six months before admission**

In Table 4.3.3C the groups were compared by subjects who have had one or more severe threat life events which was also rated as 'independent' (of their own actions). This excludes 'possibly independent' and 'dependent' life events (and so all the proportions are less than or equal to the corresponding figures in Table 4.3.3B).

**Table 4.3.3C Number of subjects with at least one severely threatening and independent life event before admission**

TIME PERIOD	Dementia Patients	Dementia Controls	Fit Elderly
0-4 weeks	14 (20%)	5 (10%)	11 (22%)
5-8 weeks	8 (11.4%)	5 (10%)	9 (18%)
9-12 weeks	7 (10%)	3 (6%)	5 (10%)
13-16 weeks	7 (10%)	4 (8%)	5 (10%)
17-20 weeks	7 (10%)	4 (8%)	3 (6%)
21-26 weeks	7 (10%)	5 (10%)	4 (8%)
0-3 months	22 (31.4%)	12 (24%)	17 (34%)
4-6 months	17 (24.3%)	11 (22%)	10 (20%)
0-6 months	29 (41.4%)	19 (38%)	20 (40%)

The pattern of results in Table 4.3.3C is much the same as in the previous table, and again there are no significant differences between the groups. In the 0-3 month period the rate of life events in the dementia patient group is 7.4% higher than the dementia control group, but as in the last set of results, if these are true differences much larger numbers would be needed to demonstrate significance.

Because of the unusually high rates of severe and independent life events in the fit elderly group a further comparison was made using the dementia patients as their own controls and comparing two time periods close to and distant from the key date. In the first analysis, the period 0-4 weeks before admission was compared with the period 13-16 weeks before admission, but there was no difference in the life event rates ( $\chi^2 = 2.02$ ,  $p = 0.16$ ). In the second analysis the number of dementia patients with severe independent life events in the first three months was compared with those experiencing life events in the period 4-6 months before admission and again there was no difference ( $\chi^2 = 0.85$ ,  $p = 0.36$ ).

#### **Severe independent plus possibly independent life events**

Using only the 'independent' criterion to look at the possible effects of life events may be too stringent criteria since they exclude events which may quite possibly be independent of the subject. This may result in a type II statistical error (i.e. finding no association where one might actually exist). It is therefore important to compare groups for independent plus possibly independent severe events, as shown in Table 4.3.3D.



**Table 4.3.3D Number of subjects with at least one severe and independent, or possibly independent, life event before admission**

TIME PERIOD	Dementia Patients	Dementia Controls	Fit Elderly
0-4 weeks	14 (20%)	5 (10%)	11 (22%)
5-8 weeks	9 (12.9%)	5 (10%)	10 (20%)
9-12 weeks	8 (11.4%)	3 (6%)	5 (10%)
13-16 weeks	8 (11.4%)	4 (8%)	5 (10%)
17-20 weeks	7 (10%)	4 (8%)	3 (6%)
21-26 weeks	7 (10%)	6 (12%)	4 (8%)
0-3 months	24 (34.3%)	12 (24%)	18 (36%)
4-6 months	18 (25.7%)	12 (24%)	10 (20%)
0-6 months	32 (45.7%)	20 (40%)	21 (42%)

As shown in Table 4.3.3D, adding possibly independent events made little difference to the percentages and none of the comparisons came close to being a significant difference. Most probabilities were around 0.5. There was a suggestion that the dementia controls actually had a lower rate of life events compared to the dementia patients ( $\chi^2 = 2.18$ ,  $p = 0.14$ ) and the fit elderly ( $\chi^2 = 2.68$ ,  $p = 0.10$ ). One implication of this is that dementia sufferers may have an intrinsically different rate of life events from the fit elderly who may not therefore be a suitable control group. There is also a possibility that the mode of informant may make a difference between the groups.



#### ***4.3.4 Life events in the three months preceding date of deterioration***

This analysis compared severe life events in the period before deterioration in the dementia patients with the three months before a comparable date in the two control groups.

If a datable deterioration was identified by the informant of a subject in the dementia patient group (within six months of admission) the life events occurring within the three months preceding this were recorded. The period up to six months before admission was chosen for two reasons: 6+3 months would give a total of a nine month's recall of life events for the informants, and dating would become progressively more difficult beyond that time, nor could the deterioration it comfortably be regarded as 'acute' in the context of this study. This enabled an examination of life events preceding deterioration rather than admission (which may actually occur for a variety of reasons other than a decline in mental functioning). If life events were more common in the dementia patients, this would suggest that life events in some way led to a deterioration in clinical condition in dementia sufferers. In the dementia patient group, 43 out of 70 (61.4%) informants were able to give a specific date for deterioration. Only 6 out of 50 (12%) dementia controls' informants gave an actual date of deterioration. This was too small a group for comparison purposes, and for the analyses and comparisons these 6 were retained in the group of 50 dementia controls. This was also done because dementia sufferers at the day centres who were in the process of a significant deterioration *had been excluded at the selection phase*. In the dementia patients the mean length of time from deterioration to admission was 13.8 weeks (standard deviation 9.7 weeks). For the subgroup of

dementia patients who had an identifiable date for *acute deterioration* (43 out of 70), the percentage with a life event in the period three months before acute deterioration is shown in Figure 4.3.4, which compares them with the life events experience of the two control groups for a comparable time period. This was considered to be for a 13 week period dating from 14-26 weeks before interview since there was an average of 14 (13.8) weeks between deterioration and admission in the dementia patients. This should balance out the possible recall bias which might have occurred if a more recent period of time had been used for the control groups. Two weeks before the deterioration date the subgroup of dementia patients had an excess of life events compared to the two control groups. 26% of the dementia patients (11 out of 43) had a life event before the deterioration date compared to only 8% (4 out of 50) in each of the two control groups. This suggests that there is an excess of life events in dementia patients in the two weeks before an identified deterioration date.

Figure 4.3.4 Percentage of subjects in each group with one or more life events preceding deterioration.

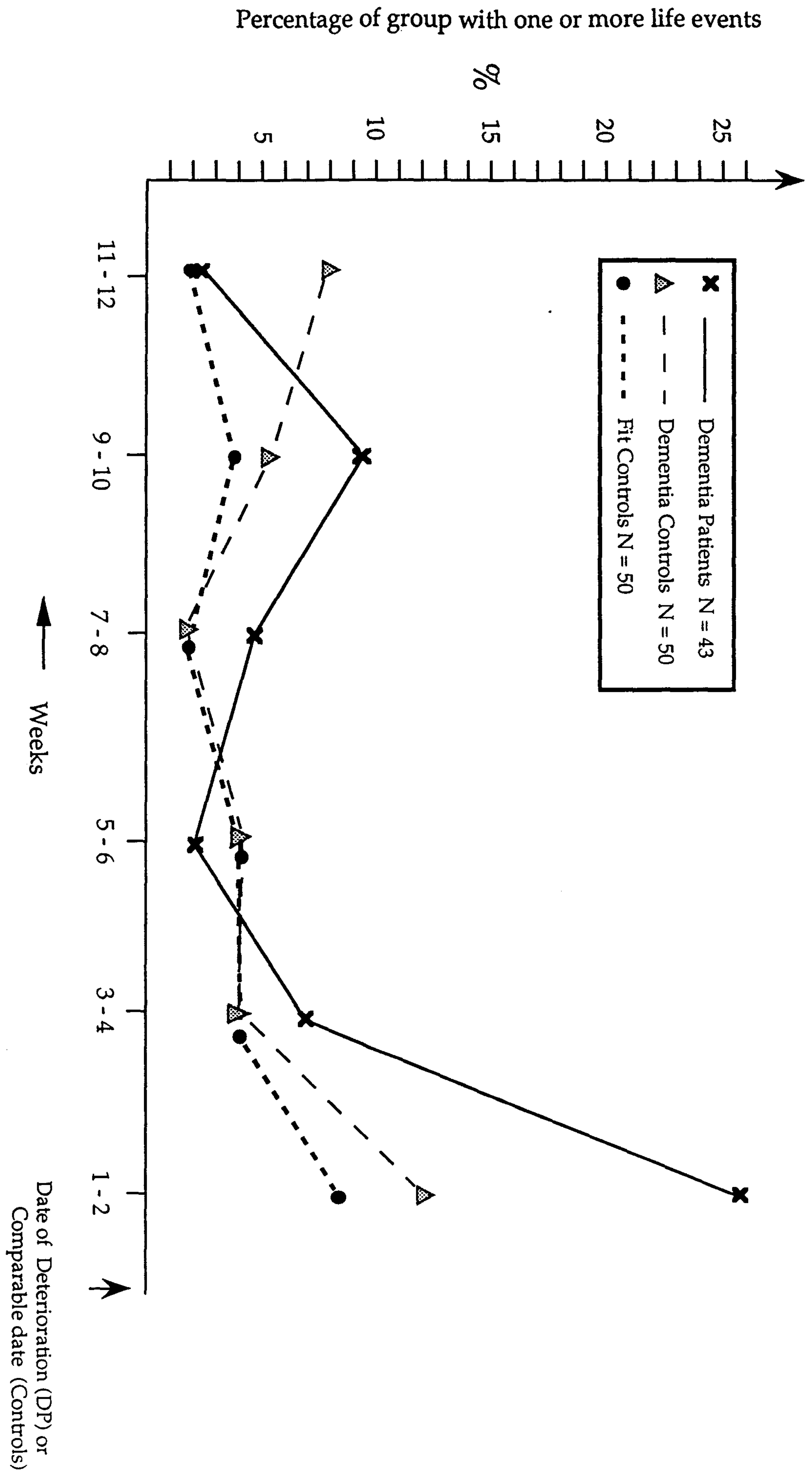




Table 4.3.4A shows the comparison between life events in the three months before deterioration (dementia patients) or a comparable period (14 weeks prior to interview) for both control groups for all types of severe life events. Table 4.3.4B compares severe and independent life events, and Table 4.3.4C compares severe and independent, or possibly independent, life events.

Table 4.3.4A Subjects with at least one severe life event before acute deterioration date (or comparable date for controls)

TIME PERIOD	Dementia Patients	Dementia Controls	Fit Elderly
0-4 weeks	11 (25.6%)	7 (14%)	4 (8%)
5-8 weeks	3 (7%)	3 (6%)	2 (4%)
9-12 weeks	5 (11.6%)	5 (10%)	3 (6%)
0-3 Months	16 (37.2%)	12 (24%)	10 (20%)
Total subjects	43	50	50

Table 4.3.4B Subjects with at least one severe and independent life event before acute deterioration date

TIME PERIOD	Dementia Patients	Dementia Controls	Fit Elderly
0-4 weeks	7 (16.3%)	7 (14%)	4 (8%)
5-8 weeks	3 (7%)	3 (6%)	2 (4%)
9-12 weeks	3 (7%)	4 (8%)	3 (6%)
0-3 Months	10 (23.3%)	12 (24%)	10 (20%)
Total subjects	43	50	50

In the first four week period before the deterioration date there was a significant excess of severe life events in the dementia patient group compared to the fit elderly

( $\chi^2 = 4.06$ ,  $p < 0.05$ ). This association did not hold for the dementia controls ( $\chi^2 = 1.31$ ,  $p = 0.25$ ). There was no association with the other time periods; in particular there was no relationship between severe events in the period 0-3 months before deterioration compared to the two control groups ( $\chi^2 = 3.51$ , 2 df,  $p = 0.17$ ).

Table 4.3.4C Subjects with at least one severe and independent, or possibly independent, life event before acute deterioration (or interview for controls)

TIME PERIOD	Dementia Patients	Dementia Controls	Fit Elderly
0-4 weeks	9 (20.9%)	7 (14%)	4 (8%)
5-8 weeks	3 (7%)	3 (6%)	2 (4%)
9-12 weeks	3 (7%)	5 (10%)	3 (6%)
0-3 Months	12 (27.9%)	12 (24%)	10 (20%)
Total subjects	43	50	50

It is interesting to note that if the four week period before interview for the dementia controls (see Table 4.3.3B) is compared with the four weeks before deterioration for the dementia patients, the dementia patients have a significantly higher rate of life events ( $\chi^2 = 3.94$ ,  $p < 0.05$ ). This pattern remains if the 5-8 week and 9-12 week periods before interview for the dementia patients are compared with the four weeks before deterioration. This suggests that although there is a general excess in the dementia patients in the four weeks before deterioration the choice of the 'comparable' time period (14-17 weeks before interview) for the dementia patients seems to be a period with an unusually high rate of life events.

There was no difference between the three groups for severe independent events occurring in any of the time periods preceding deterioration. Equally, there was no



difference between the rates of independent plus possibly independent severe events between the three groups for any of the time periods preceding deterioration.

This set of results suggested that threatening life events in themselves do not provoke deterioration but rather that in the process of deterioration dementia patients experience more life events which have been precipitated by their own behaviour and mental condition. However, further analysis was necessary because it was possible that the dementia controls who had a datable deterioration had actually experienced a higher rate of life events. This could obscure an actual difference between dementia patients and the subgroup of controls who had no datable deterioration controls. On this principle all the 6 dementia controls with a datable deterioration were excluded and the remaining 44 dementia controls were compared with the 43 dementia patients who had a datable acute deterioration.

In the dementia control (subgroup with no datable deterioration) 5 out of 44 (11.3%) had experienced a severe life event in the first four week period compared to 11 out of 43 (25.6%) of the dementia patient. This was not a significant difference ( $\chi^2 = 2.06$ ,  $p = 0.15$ ). In the full three month period 9 (20.4%) dementia controls had a severe life event compared to 16 (37.2%) dementia patients. This was also not a significant difference ( $\chi^2 = 2.22$ ,  $p = 0.14$ ). Further analyses showed no significant differences between the groups for any of the time periods, or with independent, and independent plus possibly independent, events. In short, excluding dementia controls who had datable deterioration made no particular difference to the results.



### ***4.3.5 Life events, social class and type of admission***

#### **Social class**

Because of variations in social class between the three groups, statistical comparisons were made between the occurrence of life events, social class and group looking at the periods 0-3 months, 4-6 months and 0-6 months (before admission) for severe events. The only significant association was found in the dementia control group for severe events occurring 4-6 months before assessment ( $\chi^2 = 6.17$ , 2 df,  $p < 0.05$ ). This suggested that low social class (4 or 5) was associated with a higher proportion of subjects having life events. However, when only severe and independent events were examined the association no longer held ( $\chi^2 = 3.82$ , 2 df,  $p = 0.15$ ). This suggested that the excess of life events in this group for the 4-6 month time period could be accounted for by life events which subjects may possibly have contributed to or precipitated (dependent or possibly independent).

#### **Type of admission**

Thirty-one out of the 70 dementia patients had an inpatient admission and 39 had a day patient admission. Since an inpatient admission could imply a greater degree of deterioration or a more severe breakdown in social support leading to a loss of coping factors sustaining the patient in the community, it was decided to compare life events in inpatient and day patient admissions. Life events were also compared for each of these two types of admission separately with the dementia control and fit elderly control groups.

Table 4.3.5A looks at life events in the six months before admission for the two admission groups and Table 4.3.5B compares life events in the three months prior to deterioration. Statistical comparisons were made with the two control groups. The data for the control groups are not shown in Tables 4.3.5A and 4.3.5B since it has been given in other tables in sections 4.3.3 and 4.3.4.

**Table 4.3.5A Comparison of number of dementia patients with life events preceding admission according to type of admission**

Life events	Type of Admission (total pts. in group)	0-4 weeks	0-3 months	4-6 months	0-6 months
All severe events	Inpatient	5/31 (16.1%)	12/31 (38.7%)	9/31 (29.0%)	16/31 (51.6%)
	Day patient	10/39 (25.6%)	15/39 (38.5%)	12/39 (30.8%)	22/39 (56.4%)
Severe and independent	Inpatient	5/31 (16.1%)	10/31 (32.3%)	7/31 (22.6%)	12/31 (38.7%)
	Day patient	9/39 (23.1%)	12/39 (30.8%)	10/39 (25.6%)	17/39 (43.6%)
Severe independent and poss. independent	Inpatient	5/31 (16.1%)	11/31 (35.5%)	7/31 (22.6%)	13/31 (41.9%)
	Day Patient	9/39 (23.1%)	13/39 (33.3%)	11/39 (28.2%)	19/39 (48.7%)

None of the comparisons in Tables 4.3.5A and 4.3.5B were significantly different according to type of admission, or comparing each type of admission with each of the two control groups of dementia controls and fit elderly. However, in the 0-4 week time period (before admission) looking at all severe life events, there was a suggestion of

a difference between the day patients and the day centre attenders. Ten out of 39 (25.6%) day patients experienced severe life events compared to only 5 out of 50 dementia controls (day centre).  $\chi^2$  was 2.79 which gave a probability of 0.095. These results do not support the suggestion that type of admission is linked with the occurrence of life events.

Table 4.3.5B Comparison of life events preceding acute deterioration in the dementia patient group according to type of admission

Life events	Type of Admission (total pts in group)	0-4 weeks	0-3 months
All severe events	Inpatient (22)	4/22 (18.2%)	8/22 (36.4%)
	Day patient (21)	7/21 (33.3%)	8/21 (38.1%)
Severe and independent	Inpatient (22)	3/22 (13.6%)	5/22 (22.7%)
	Day patient (21)	4/21 (19.0%)	5/21 (23.8%)
Severe and independent and possibly independent	Inpatient (22)	3/22 (13.6%)	5/22 (22.7%)
	Day Patient (21)	6/21 (28.6%)	7/21 (33.3%)



### ***4.3.6 Life events, cognition and mood***

#### **Life events and severity of dementia**

In order to investigate the effect of the severity of dementia on life events, an analysis was done stratifying for group looking at life events according to degree of dementia. The theoretical arguments for doing this were that people with severe dementia may have a declining social field and so have fewer life events, or on the other hand the worsening dementia and function may precipitate life events (dependent).

Tables 4.3.6A, 4.3.6B and 4.3.6C show the proportion of subjects with severe, severe independent, and severe and independent plus possibly independent life events according to the severity of the dementia in each of the two dementia groups (before admission).

In Table 4.3.6A the patient group with mild dementia has the highest proportion of life events overall in all the three time periods. This could suggest that those with mild dementia are in some way more susceptible to severe life events. Life events could either act directly, producing distress or impaired functioning, or indirectly, stressing carers and reducing their ability to cope with a particular level of cognitive deficit, behavioural disturbance and dependency. However, restricting the analysis to those subjects with mild or moderate dementia and comparing the two dementia groups there is still no significant difference between patients and controls. For the 0-3 month time period  $\chi^2$  is 2.35 ( $p = 0.13$ ) and for the 0-6 month time period  $\chi^2$  is 0.62 ( $p = 0.43$ ).

**Table 4.3.6A Proportion of subjects with a severe life event by severity of dementia (cognitive impairment) and group (before admission)**

Subject Group	Severity of dementia (total in group)	number with one or more severe life events		
		0-3 months	4-6 months	0-6 months
Dementia Patients	mild (11)	7 (63.6%)	5 (45.4%)	8 (72.7%)
	moderate (25)	9 (39.1%)	4 (16%)	11 (44%)
	severe (27)	9 (33.3%)	9 (33.3%)	15 (55.5%)
	very severe (7)	2 (28.6%)	3 (43.9%)	4 (57.7%)
Dementia Controls	mild (6)	1 (16.7%)	2 (33.3%)	3 (50%)
	moderate (24)	6 (25%)	6 (25%)	9 (37.5%)
	severe (17)	5 (29.4%)	4 (23.5%)	8 (47.1%)
	very severe (3)	0 (of 3)	1 (33.3%)	1 (33.3%)

Looking at Table 4.3.6B the general pattern remains of an apparently higher frequency of life events in the mild dementia patient subgroup compared to the other patient and control subgroups. But once again there is no significant difference in life event frequency between the patients or controls for any of the time periods looking at the mild/moderate dementia subgroup. For the 0-3 month period  $\chi^2 = 0.38$  ( $p = 0.54$ ) and for the 0-6 month time period  $\chi^2 = 0.03$  ( $p = 0.87$ ). This again suggests there is no relationship between frequency of life events and subject group for those with mild/moderate dementia.

In order to examine any relationship between severity *per se* and the occurrence of life groups: mild/moderate dementia and severe/very severe dementia first for the



dementia patients and then for the dementia controls. An analysis was also done using a combined group of all dementia subjects. No significant differences were found in any of the comparisons.

**Table 4.3.6B Proportion of subjects with an independent severe threat life event by severity of dementia (cognitive impairment) and group**

Subject Group	Severity of dementia (total in group)	one or more independent severe life event		
		0-3 months	4-6 months	0-6 months
Dementia Patients	mild (11)	6 (54.5%)	5 (45.4%)	7 (63.6%)
	moderate (25)	6 (24%)	3 (12%)	7 (28%)
	severe (27)	8 (29.6%)	7 (25.9%)	12 (44.4%)
	very severe (7)	2 (28.6%)	2 (28.6%)	3 (42.9%)
Dementia Controls	mild (6)	1 (16.7%)	2 (33.3%)	3 (50%)
	moderate (24)	6 (25%)	6 (25%)	9 (37.5%)
	severe (17)	5 (29.4%)	2 (11.8%)	6 (35.3%)
	very severe (3)	0 (of 3)	1 (33.3%)	1 (33.3%)

In order to see if life events appeared to be related to severity of cognitive impairment a logistic regression analysis was performed including the other variables which could be important in relation to the dementia patient and dementia control groups. This analysis is described in more detail in section 3.5.0. Logistic regression was performed using severe and independent life events occurring in the 6 month period prior to admission as the dependent variable. The other variables included were, severity of cognitive impairment, age, educational level, social class and group.



This type of analysis was chosen because it can employ a mixture of categorical and continuous variables and because it allows the relative contributions of each of the variables to be taken into account. It also avoids the necessity of stratifying the sample which in turn reduces the group size, or of condensing the groups which can be a necessary drawback of using  $\chi^2$  analysis. Entering all the variables into the equation, none reached a significant level of probability, as shown in Table 4.3.6C.

**Table 4.3.6C Logistic regression analysis of variables associated with life events**

----- Variables in the Equation -----							
Variable	B	S.E.	Wald	df	Signif.	R	Exp(B)
GROUP	.003	.199	0.000	1	.987	.000	1.003
SOCIAL CLASS	-.134	.216	0.382	1	.537	.000	.875
AGE	.006	.023	0.069	1	.793	.000	1.006
COGNITIVE IMP.	.187	.186	1.012	1	.314	.000	.830
EDUCATION	.344	.285	1.456	1	.228	.000	1.411
Constant	.395	2.07	0.036	1	.849		

To further assess the associations of these variables with the six month experience of severe independent life events, the log likelihood ratio method was used to remove those variables which did not make a significant contribution at each stage of the model. The forward stepwise selection procedure removes those with the highest probability values in order to improve the goodness of fit of each successive model. None of the variables made any significant contribution to the model and so in a stepwise fashion all were removed. This suggests that none of these variables have any association with such life events in dementia sufferers.

The logistic regression analyses above were repeated looking at severe independent life events in the four weeks and in the three months prior to admission and compared with the dementia control groups. Again, none of the results were significant, suggesting a lack of associations between these factor and life events prior to acute deterioration.

**Depressive symptoms and life events**

As noted in the introduction, previous studies have shown a relationship between stressful life events and depression in the elderly. Tables 4.3.6D and 4.3.6E compare subjects with any depressive symptoms (as indicated by a score of 1 or more for depression on the GMSS) with subjects without depressive symptoms in terms of their experience of 1 or more severe life events within the time period defined.

Table 4.3.6D Proportion of subjects with a severe life event by depressive symptoms and group

GROUP	Depressive Symptoms	one or more severe life events		
		0-3 months	4-6 months	0-6 months
Dementia Patients	YES	7/14 (50%)	9/14 (64%)	11/14 (79%)
	NO	20/56 (36%)	12/56 (21%)	27/56 (48%)
Dementia Controls	YES	5/13 (38%)	6/13 (46%)	8/13 (62%)
	NO	7/37 (19%)	7/37 (19%)	13/37 (35%)
Fit Controls	YES	2/8 (25%)	1/8 (13%)	2/8 (25%)
	NO	16/42 (38%)	9/42 (21%)	19/42 (45%)

With dementia sufferers there are difficulties in dating the exact onset of depressive symptoms because they generally cannot specify dates accurately. Nevertheless, the



results might suggest that life events could be risk a factor in the development of depressive symptoms in dementia sufferers.

The results in Table 4.3.6D showed a highly significant association ( $p < 0.003$ ) between depressive symptoms and the occurrence of a severe life event 4-6 months prior to admission in the dementia patient group. In addition, for the dementia patients the 0-6 month period almost reached significance. For the dementia controls all three comparisons had a probability of less than 0.2 suggesting a possible link meriting more detailed investigation. Since this result could be a spurious effect of the subject precipitating a life event themselves, the results were further analysed looking only at severe independent life events as shown in Table 4.3.6E.

Table 4.3.6E Proportion of subjects with a severe and independent life event by depressive symptoms and group

GROUP	Depressive Symptoms	one or more severe and independent life events		
		0-3 months	4-6 months	0-6 months
Dementia Patients	YES	7/14 (50%)	8/14 (57%)	11/14 (79%)
	NO	15/56 (27%)	9/56 (16%)	18/56 (32%)
Dementia Controls	YES	5/13 (38%)	6/13 (46%)	8/13 (62%)
	NO	7/37 (19%)	5/37 (14%)	11/37 (30%)
Fit Controls	YES	2/8 (25%)	1/8 (13%)	2/8 (25%)
	NO	15/42 (36%)	9/42 (21%)	18/42 (43%)



In Table 4.3.6F the association between depressive symptoms and severe independent life events in the 4-6 month period (before admission or interview) remains highly significant ( $p < 0.004$ ) for the dementia patients and reaches the  $p = 0.02$  significance level for the dementia controls. In addition for both of these groups the 0-6 month periods are significant at the  $p < 0.05$  level. Also, for the 0-3 month periods the probabilities are low ( $p = 0.09$  and  $p = 0.15$ ) suggesting a tendency towards significance which might be demonstrated with larger groups. This makes a stronger case for a link between depressive symptoms and life events in subjects with dementia.

There appears to be no relationship between depressive symptoms and life events in the fit elderly control group (as has been found in other studies), this may be accounted for because the study design excluded subjects with depression in this control group.

In order to look at the possible contributions of other factors in relation to the occurrence of depressive symptoms, a logistic regression analysis was performed including presence or absence of depressive symptoms as the dependent variable and including the two dementia groups. The independent variables were chosen to reflect factors which may be important in depression or seemed important in differentiating the two groups. The principle aim was to see if life events were still linked with depressive symptoms when the effects of other factors were controlled for. The independent variables chosen were: group (dementia patients or dementia controls), age, social class, severity of cognitive impairment, conflict (negative communication) and severe independent life events in the previous 4-6 months (to admission or

interview). In the first analysis all the variables were entered and the relative contributions of each to the model are shown in Table 4.3.6F. From this analysis it is evident that only age and life events make a significant contribution to the risk of depressive symptoms when all the variables are included in the model.

**Table 4.3.6F Logistic regression analysis looking at variables associated with depressive symptoms in dementia sufferers**

----- Variables in the Equation -----							
Variable	B	S.E.	Wald	df	Signif.	R	Exp(B)
DEM. GROUP	.125	.389	.103	1	.749	.000	1.132
SOCIAL CLASS	.049	.314	.024	1	.876	.000	1.050
AGE	.089	.053	2.822	1	.093	.114	1.093
COGNITIVE IMP.	-.424	.292	2.107	1	.147	-.041	.655
CONFLICT	-.041	.244	.029	1	.865	.000	.959
LIFE EVENTS	-.813	.367	4.901	1	.027	-.215	.443
Constant	-6.335	4.174	2.304	1	.129		

The forward stepwise selection procedure was then used to select out (in order) all those variables which did not make significant contributions to the goodness of fit of the model. The final results are shown in Table 4.3.6G. As a result of the forward stepwise procedure all the variables but life events and age were removed, suggesting that these are the only risk factors for depression in dementia patients.

**Table 4.3.6G Logistic regression analysis likelihood ratios after forward stepwise selection procedure for variables associated with depressive symptoms**

----- Model if Term Removed -----				
Term	Log	-2 Log L	Significance	
Removed	Likelihood	Ratio	df	of Log LR
AGE	-31.991	3.985	1	.0459
LIFE EVENTS	-33.386	6.776	1	.0092

To assess further the risk factors associated with depressive symptoms, the analyses were repeated using age and dementia group, and again repeated entering age, dementia group and life events. After dementia group (patients or controls) was selected out, the probability for age fell to  $p = 0.032$  and the probability associated with life events fell to  $p = 0.0002$  (or 1 in 5000). These results support the findings that life events in the previous 4-6 months and (to a lesser extent) increasing age, are associated with an increasing risk of depression in dementia sufferers.

The logistic regression analysis was repeated using the same variables but substituting severe independent life events in the 0-3 months preceding admission for life events in the 4-6 month period. In this instance, age ( $p = 0.030$ ), and life events ( $p = 0.034$ ) were again both significantly associated with depressive symptoms.

In a final analysis, severe independent life events in the three months before acute deterioration were substituted in the analysis and only life events ( $p = 0.013$ ) were significantly associated with depressive symptoms, but age ( $p = 0.070$ ) came close.



## Anxiety symptoms and life events

As there appeared to be a high proportion of dementia subjects with anxiety symptoms and a possible link between life events and depressive symptoms, it was necessary to examine links between life events and anxiety symptoms. The results concerning severe and independent severe life events are shown in Tables 4.3.6H and 4.3.6I.

Table 4.3.6H Subjects with a severe life event by anxiety symptoms and group

GROUP	Anxiety Symptoms	one or more severe life events		
		0-3 months	4-6 months	0-6 months
Dementia Patients	YES	7/20 (35%)	10/20 (50%)	11/20 (55%)
	NO	20/50 (40%)	11/50 (22%)	27/50 (54%)
Dementia Controls	YES	5/16 (31%)	6/16 (38%)	8/16 (50%)
	NO	7/34 (19%)	7/34 (21%)	13/34 (38%)
Fit Controls	YES	4/10 (40%)	3/10 (30%)	5/10 (50%)
	NO	14/40 (35%)	7/40 (18%)	16/40 (40%)

Table 4.3.6I Subjects with an independent severe threat life event by anxiety symptoms and group

GROUP	Anxiety Symptoms	one or more independent severe life events		
		0-3 months	4-6 months	0-6 months
Dementia Patients	YES	7/20 (35%)	8/20 (40%)	11/20 (55%)
	NO	15/50 (30%)	9/50 (18%)	18/50 (36%)
Dementia Controls	YES	5/16 (31%)	5/16 (31%)	8/16 (50%)
	NO	7/34 (21%)	6/34 (18%)	11/34 (32%)
Fit Controls	YES	4/10 (40%)	3/10 (30%)	5/10 (50%)
	NO	13/40 (35%)	7/40 (18%)	15/40 (38%)

In the analysis of Table 4.3.6H there is a highly significant association between severe life events occurring 4-6 months before admission and anxiety symptoms ( $\chi^2 = 5.92$ ,  $p = 0.01$ ) in the dementia patients. Moreover, this relationship remains when independent severe life events were examined, as in Table 4.3.6I (Fishers's,  $p = 0.03$ ). None of the other comparisons in these two tables are significant.

A logistic regression analysis was performed looking at anxiety symptoms with respect to: life events (severe independent in the preceding 4-6 months), depressive symptoms, social class, age and dementia group. Only depressive symptoms ( $p = 0.000$ ) and age ( $p = 0.025$ ) were significantly associated with the presence of anxiety symptoms. This indicates that the link between life events and anxiety is likely to be secondary to the stronger association between depressive symptoms and life events.

The results of the comparisons of depressive and anxiety symptoms and life events suggest that individuals with dementia are particularly sensitive to the effects of life events and this gives rise to symptoms of distress such as depressive and anxiety symptoms. The dementia patient group appear to be more sensitive to the effects of life event effects in terms of developing such symptoms. The life events could act on the dementia sufferer after a delay, causing symptoms of depression and anxiety which may manifest as deterioration and so lead to admission. On the other hand the anxiety and depressive symptoms may have started soon after the life event but persisted until admission or the interview date. As the symptoms of anxiety and depression were not dated, there remains the possibility that in some individuals the anxiety or depressive symptoms preceded the life event experience.



### ***4.3.7 Life events, behaviour and acute deterioration***

From the theoretical point of view it was possible that life events may in some way undermine coping mechanisms and so lead to behavioural disturbance and deterioration. For this reason it was judged important to look at differences in life events, CAPE scores, and acute deterioration, comparing the dementia patient and dementia control groups.

#### **Life events, behavioural disturbance and dependency ratings**

Although the overall CAPE scores did not differ between the dementia patient and dementia control groups, certain items appeared to be more of a problem in the dementia patient group. It was conceivable that life events might be more likely to precipitate certain types of behaviour disturbance. For this reason CAPE items which appeared to occur with differing frequencies in the two dementia groups were looked at with respect to life events. Also compared were two other CAPE questions which were closely related to questions in the acute deterioration scale and which differed between the two groups. This should reveal whether life events might in some way increase the risk of particular types of behavioural problems although the theoretical reasons for expecting an association were stronger for some items than for others. Question numbers corresponding to the CAPE are listed in brackets.

The time periods used were 0-3 months, 4-6 months, and 0-6 months before admission, and the life event categories were severe and independent severe life events.



The comparisons were made between the two dementia groups using the questions below:

- (3) Incontinence
- (5) Confusion/losing things (cognitive impairment/memory and orientation).
- (15) Objectionable behaviour at night
- (17) Hoarding
- (18) Sleeping difficulties

Incontinence, hoarding, objectionable night behaviour and sleep disturbance had no significant association with life events for either group. However, for the dementia patient group (but not the dementia controls) significant associations were found, but only between degree of cognitive impairment and:

1. Severe life events in the past 0-6 months ( $\chi^2 = 3.87$ ,  $p < 0.05$ )
2. Independent severe life events in the past 0-6 months ( $\chi^2 = 6.78$ ,  $p < 0.01$ )

Looking at the total CAPE score, no differences were found between the different dependency groups (comparing moderate dependency or less (CAPE 0-12), with severe dependency or more (13-36) for life events in either group). As a further analysis, the t-test was used (Tables 4.3.7A and 4.3.7B) to compare those with and without life events. The lack of any significant differences between the groups in these two tables suggests that there is no relationship between life events and CAPE score in either dementia patient or dementia control groups. Nor is there a relationship between life events and CAPE score when comparing dementia patient with dementia control groups.

**Table 4.3.7A CAPE behavioural scores: means and t-test comparing within dementia groups for subgroups with and without severe life events (before admission)**

	Time period	Mean: life events	Mean: no life events	t	probability
Dementia Patients	0-3 months	13.42	14.67	- 0.81	0.42
	4-6 months	15.25	13.78	0.37	0.37
	0-6 months	13.78	14.69	- 0.60	0.50
Dementia Controls	0-3 months	15.17	13.51	0.83	0.41
	4-6 months	13.77	13.97	- 0.10	0.92
	0-6 months	14.24	13.68	0.32	0.75

All the comparisons in the tables and t-tests were repeated using independent severe life events and again no significant differences were found. In Table 4.3.7B does not appear to be any trends towards an association.

**Table 4.3.7B CAPE behavioural scores: means and t-test comparing subgroups with and groups without severe life events (before admission) by subject group means**

	Time period	Mean: Dementia Patients	Mean: Dementia Controls	t	probability
Life Events	0-3 months	13.42	15.17	- 0.76	0.45
	4-6 months	15.25	13.77	0.69	0.50
	0-6 months	13.78	14.24	- 0.27	0.79
No Life Events	0-3 months	14.67	13.51	0.88	0.38
	4-6 months	13.78	13.97	- 0.15	0.89
	0-6 months	14.69	13.68	0.64	0.52

### **Acute deterioration and life events**

In many subjects it had been possible to date the onset of a specific period of acute deterioration. However, because senile dementia is an illness which tends to deteriorate over time, it was considered important to look at the acute deterioration scale with respect to life events. This was because, theoretically dementia subjects experiencing life events may deteriorate more than those without life events, and, the acute deterioration scale appeared to be a reasonable measure of that deterioration. As with the CAPE score, certain items of the acute deterioration score appeared to distinguish between the two dementia groups and these were therefore included in the comparisons with respect to life events. In addition, the possible relationship between life events and the total acute deterioration score was investigated.

The categories examined were severe life events and also independent severe life events over the time periods: 0-3 months, 4-6 months, 0-6 months prior to admission. For the analyses the items included from the acute deterioration score were those which were most significantly different between dementia patient and dementia control groups:

- a) Restless/wandering behaviour
- b) Cognitive deterioration
- c) Sleep disturbance

Initially the analysis focused on the possible links between life events and acute deterioration within the individual dementia groups.



Increased wandering/restlessness appeared to be related to severe (Fisher's exact,  $p < 0.05$ ) and independent severe (Fisher's exact,  $p < 0.05$ ) life events occurring in the period 0-3 months before admission in the dementia patient group. This may suggest that the experience of a life event makes such individuals prone to wander because of distress or of disturbance to their daily routine. If life events cause this behaviour it may in turn lead to admission. On the other hand wandering behaviour may precipitate life events (such as accidents or physical disorders, such as hypothermia).

Increased sleep disturbance had a number of significant associations but only within the patient group:

1. Severe life events in the past 4-6 months ( $\chi^2 = 9.11$ ,  $p = 0.01$ )  
and at 0-6 months ( $\chi^2 = 6.18$ ,  $p < 0.05$ )
2. Independent severe life events in the past 0-3 months ( $\chi^2 = 6.67$ ,  $p < 0.05$ ),  
4-6 months and 0-6 months ( $\chi^2 = 8.55$ ,  $p = 0.01$ ).

Increased cognitive deterioration had a number of significant associations found in the patient group:

1. Severe life events in the past 0-3 months ( $\chi^2 = 5.51$ ,  $p < 0.05$ ), and 0-6 months ( $\chi^2 = 4.86$ ,  $p < 0.05$ ).
2. Independent severe life events in the past 0-3 months ( $\chi^2 = 5.38$ ,  $p < 0.05$ )  
and 0-6 months ( $\chi^2 = 5.51$ ,  $p < 0.01$ ).

These results suggest that certain aspects of deterioration such as cognitive decline, sleep disturbance, and restless/wandering behaviour may be predated by severe and

independent life events. It is possible that the life events may in some way precipitate these aspects of deterioration in certain individuals with dementia. It also may be that informants are biased towards reporting these types of deterioration if they are aware of life events happening to the subject. In particular, reported cognitive problems appear to be linked with life events in the previous six months, although this was not supported by the results in section 4.3.6 looking at life events in relation to the severity of cognitive impairment assessed at interview (using the GMSS). Previous differences found between the two groups on the acute deterioration score could be linked with life events, in that people who had life events may be rated as more deteriorated by their informant compared to those people without events. It may be that the informant report was a more sensitive measure of subtle cognitive change than the GMSS scale. It could also be that there was a degree of bias in the informant's reporting such that if they were aware of a life event, they may have expected, and so reported, more cognitive change in the individual dementia sufferer.

Comparisons were made between the dementia groups looking at whether or not they had severe life events occurring within the set time periods, and the mean acute deterioration scores.

Table 4.3.7C shows that within the groups there was no difference between the acute deterioration scores of those with and without life events. The most interesting result is that there appears to be a slightly higher deterioration score for those dementia controls who had life events in the past three months. This is unlikely to be due to observer bias since the interview was conducted in such a way that the recording of



life events was always carried out after the assessment of acute deterioration. Nevertheless, the possibility of some degree of observer bias cannot be ruled out. There could be an effect of bias because the informant may link life events and deterioration. The results could suggest that life events precede deterioration or even that informants who were aware of the events perceived the subjects as more deteriorated.

Table 4.3.7C Acute deterioration scores: means and t-test comparing within dementia groups for subgroups with and without severe life events

	Time period (before admission)	Mean: life events	Mean: no life events	t	probability
Dementia Patients	0-3 months	10.44	9.72	1.09	0.28
	4-6 months	10.43	9.79	0.93	0.35
	0-6 months	10.30	9.62	1.07	0.29
Dementia Controls	0-3 months	7.08	4.58	1.74	0.09
	4-6 months	4.69	5.35	- 0.46	0.65
	0-6 months	5.62	4.86	0.59	0.56

Table 4.3.7D shows the differences between the mean scores of subjects in the two dementia groups who had or had not had life events. A previous analysis had already shown that the acute deterioration score was higher in dementia patients compared to dementia controls. This analysis examined whether differences in scores may in part be due to life events differences. All the results were significant or highly significant whether or not the person had experienced life events. In addition, all the analyses were repeated using independent severe events and the t-test and again all the results



were significant regardless of the occurrence of life events. This suggested that life events and the acute deterioration score are unrelated.

Table 4.3.7D Acute deterioration scores: means and t-test comparing subgroups with and groups without severe life events by subject group means

	Time period (before admission)	Mean: Dementia Patients	Mean: Dementia Controls	t	probability
Life Events	0-3 months	10.44	7.08	2.39	0.02*
	4-6 months	10.43	4.69	3.91	0.00*
	0-6 months	10.30	5.62	4.33	0.00*
No Life Events	0-3 months	9.72	4.58	7.27	0.00*
	4-6 months	9.79	5.35	6.23	0.00*
	0-6 months	9.63	4.86	6.05	0.00*

In a further analysis, the two dementia groups were merged and acute deterioration score was compared for dementia sufferers with and without life events. Both severe and independent severe life events were compared for the 0-3, 4-6, and 0-6 month periods preceding admission. For the 0-6 and 4-6 month periods there were no associations. However, severe life events in the 0-3 month period were associated with a higher mean acute deterioration score ( $t = -2.49$ ,  $p = 0.014$ ). When only independent severe events were included this association remained although it was less pronounced ( $t = -2.02$ ,  $p = 0.046$ ).

Although the results so far in this section suggest associations between life events, and CAPE items, acute deterioration items, and the acute deterioration score, it is important to try and control for the effects of the different variables. As discussed, the

best method for doing this, given the characteristics of the data, is logistic regression analysis.

### **Logistic regression analysis - factors discriminating between the dementia groups**

This analysis was performed using group membership (dementia patient or dementia control) as the dependent variable. In this way it was possible to see what factors predicted group membership. This enabled an assessment of whether life events were associated with group membership when other psychiatric variables were controlled for. It also allowed testing of the hypothesis that life events were associated with deterioration and so led to admission. After the first analysis, the analyses were repeated, each time entering a different life event category as a new independent variable. The other independent variables were chosen from those factors which appeared to be important in terms of psychiatric symptoms between the two dementia groups. The analysis was repeated, each time including one of the life events categories. None of the categories of life events were significantly associated with membership of a particular dementia group.

The independent variables included:

- Age, cognitive impairment and depressive symptoms (GMSS)
- CAPE score and Acute Deterioration Score
- Duration of illness

The life event periods chosen were:

- Independent severe life events occurring 0-6 months, 0-3 months and 4-6 months before admission
- Severe and independent severe life events occurring in the 0-4 week period before deterioration and in the 0-3 month period before deterioration

In the analysis as shown in Table 4.3.7E the overall scores of the CAPE and Acute deterioration make a significant contribution to the model, and depressive symptoms almost justify inclusion. These results are understandable, as deterioration is likely to be more of a problem in the dementia patients since it may precipitate admission.

**Table 4.3.7E Logistic regression analysis likelihood ratios after forward stepwise selection procedure for variables associated with group**

----- Model if Term Removed -----				
Term	Log	-2 Log L		Sig. of
Removed	Lik.	Ratio	df	Log LR
DEPRESSION	-51.38	3.73	1	.0536
CAPE score	-54.76	10.49	1	.0012
ACUTE DETERIORATION score	-74.59	50.15	1	.0000

The analysis was also repeated entering each category of life events (in turn) *before* the Acute Deterioration score and the CAPE score, and no relationship between life events and group was found. This confirms that there appears to be no overall difference between the two dementia groups in the rate of severe independent life



events which they experience. Hence, independent life events of severe threat do not appear to precipitate acute deterioration and admission in senile dementia sufferers. Another hypothesis was that life events led to depressive symptoms in the dementia sufferers which then led to an admission. This was tested using dementia group as the dependent variable and entering life events before depressive symptoms in the first series of analyses, and depressive symptoms before life events in the second series of analyses. Once again, life events did not contribute to the model. Although life events were associated with depressive symptoms (as shown in earlier analyses), and depressive symptoms showed a trend towards being associated with admission (Table 4.3.6D), life events were not linked with admission via depressive symptoms.

### 4.3.8 Life events, routine and environment

In section 4.2.0 the reliability of the new method of rating changes in the subject's routine and environment was tested and found to be satisfactory. This part of the analysis examines the possible contribution routine and environment changes make to the overall effects of life events. Table 4.3.8A shows the distribution of events with respect to the dimensions of environment and routine change. Out of the total of 206 life events experienced by all subjects, 72 (35.0%) life events had changes in routine or environment or both. These comprised 35 (17.0%) life events which had changes in routine only, 13 (6.3%) life events which had changes in environment only and 24 (11.7%) which had changes in both environment and routine. There was a highly significant association (Kendall's tau = 0.361,  $p = 0.000$ ) between degree of routine and environment change.

Table 4.3.8A The routine and environment dimensions of life events

TOTAL NUMBER OF LIFE EVENTS = 206		Degree of Environment Change					
		None	Mild	Moderate	Severe	Extreme	Any
Degree of Routine Change	None	134	3	6	4	0	13
	Mild	12	0	3	2	2	7
	Moderate	14	1	6	2	1	10
	Severe	7	0	1	5	1	7
	Extreme	2	0	0	0	0	0
	Any	35	1	10	9	4	72

Figure 4.3.8A Percentage of subjects with life events with change in routine.

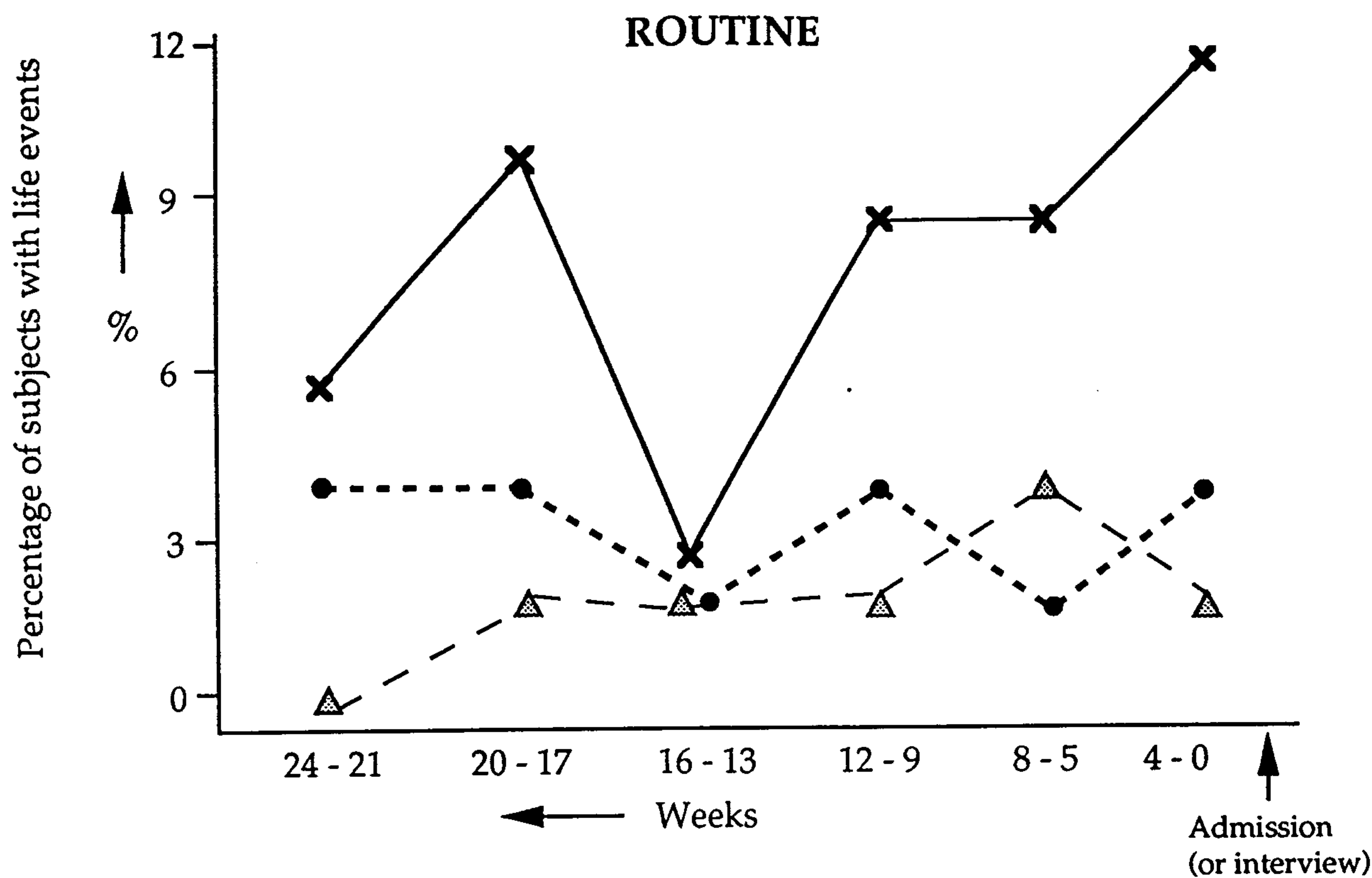
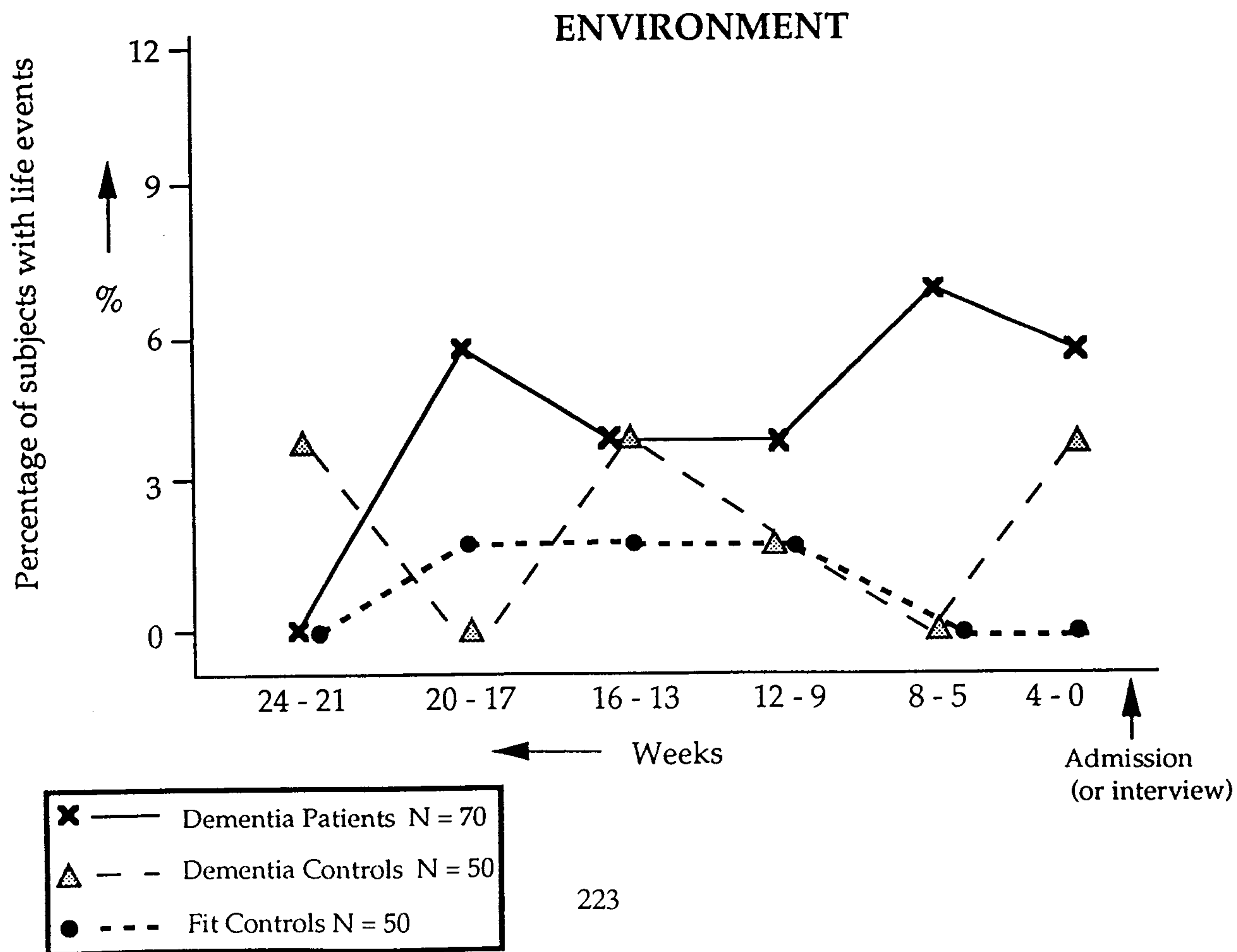


Figure 4.3.8B Percentage of subjects with life events with change in environment.





It was hypothesised that dementia patients would be more likely to have experienced life events which disrupted their routine or environment, and that these would precipitate deterioration in functioning which in turn would precipitate admission. Figures 4.3.8A and 4.3.8B shows the proportions of subjects experiencing life events with routine (4.3.8A) or environment (4.3.8B) change. Overall, the dementia patients appear to have had more life events with routine and environment change than the two control groups. This difference seems to be most marked with routine change life events occurring in the 12 weeks preceding admission. The graphs were not repeated looking at environment and routine change life events before deterioration because of the small numbers involved in many of the categories.

#### **Life events and change in routine**

In Table 4.3.8B the number of all types of life events in the past six months with some element of routine change is shown for each group. It shows that a much higher proportion of dementia patients had routine changes associated with their life events compared to the two control groups.

Because of the small numbers in some of the groups, statistical comparisons were made between the life events with no change and those with some degree of routine change (score 1-4). The dementia patients had a significantly higher rate of routine disrupting life events than the dementia controls ( $\chi^2 = 10.87$ ,  $p = 0.001$ ) or the fit elderly ( $\chi^2 = 5.11$ ,  $p = 0.02$ ). There was no difference between the two control groups ( $\chi^2 = 0.39$ ,  $p = 0.53$ ). This suggests that the element of life events which disrupts a dementia sufferers 'routine' may in some way contribute to decompensation or

deterioration leading to presentation to services. However, at this stage it is not known if these are severe or independent events. It may simply be that the dementia sufferer is precipitating the life events which change their routine as a consequence of their deteriorating condition.

Table 4.3.8B Number of life events with routine change

Degree of routine change linked with life event	Dementia Patients	Dementia Controls	Fit Elderly
No change (0)	51	47	37
Mild change (1)	12	1	4
Moderate change (2)	15	1	3
Severe change (3)	7	4	2
Extreme change (4)	1	1	0
Life events with any change in routine (1-4)	35 (40.7%)	7 (13.0%)	9 (19.6%)
Total life events	86	54	46

The next analysis compared subjects who had life events involving routine change with all levels of severity of threat and for varying degrees of independence. All levels of threat were examined since it was considered possible that if it was principally the *routine* component which disrupted the person's coping mechanisms and clinical state it may be this, rather than simply the overall threat, which was important in precipitating deterioration. Because very few individuals (5) had more than one life event with a routine change, for the purposes of analysis the groups were separated into those with or without at least one life event containing routine change. The results of the comparisons are shown in Table 4.3.8C.



**Table 4.3.8C Subjects with one or more life events containing a change in routine in time period**

		Dementia Patients	Dementia Controls	Fit Elderly
All	0-3 months	19/70 (27.1%)	4/50 (8%)	5/50 (10%)
	4-6 months	14/70 (20%)	3/50 (6%)	5/50 (10%)
	0-6 months	30/70 (42.9%)	6/50 (12%)	10/50 (20%)
All Independent	0-3 months	10/70 (14.3%)	3/50 (6%)	5/50 (10%)
	4-6 months	12/70 (17.1%)	1/50 (2%)	4/50 (8%)
	0-6 months	19/70 (27.1%)	4/50 (8%)	9/50 (18%)
All Independent and Possibly Independent	0-3 months	15/70 (21.4%)	3/50 (6%)	5/50 (10%)
	4-6 months	13/70 (18.6%)	2/50 (4%)	5/50 (10%)
	0-6 months	25/70 (35.7%)	5/50 (10%)	10/50 (20%)

Taking all events (including dependent ones) there was a general excess of events with routine change in the dementia patient group compared to the other two groups. This was a highly significant difference for events in the periods 0-3 months ( $\chi^2 = 9.92$ ,  $p = 0.007$ ) and 0-6 months ( $\chi^2 = 15.86$ ,  $p = 0.0004$ ) before admission, and almost reached significance for the 4-6 months time period ( $\chi^2 = 5.62$ ,  $p = 0.060$ ).

Including independent life events only, meant that the 4-6 month ( $\chi^2 = 7.75$ ,  $p = 0.021$ ) and 0-6 month ( $\chi^2 = 7.03$ ,  $p = 0.030$ ) periods had a significantly higher rate of life events in the dementia patient group but the 0-3 month period did not ( $\chi^2 = 2.14$ ,  $p = 0.343$ ). When independent and possibly independent events were both included there was a significant excess in the dementia patients for each of the 0-3 month ( $\chi^2$



= 6.69,  $p = 0.035$ ), 4-6 month ( $\chi^2 = 6.18$ ,  $p = 0.046$ ) and 0-6 month ( $\chi^2 = 11.21$ ,  $p = 0.0037$ ) time periods before admission.

Overall, the main difference appears to be a considerably greater frequency of life events with routine change in the dementia patient group compared to the dementia controls and to a lesser extent the fit controls. This suggests that the disruptive element of routine change life events may have a role in causing the deterioration in dementia subjects leading to admission. This pattern was consistent whether independent or independent plus possibly independent events were used for the analysis.

#### Relative risk of admission after routine change life event

To assess the chances of admission after a subject with dementia has experienced a routine change life event, the relative risk (odds ratio) and 95% confidence intervals (CI) were calculated for life events over the 0-6 month period before admission. Thirty (43%) dementia patients had experienced a life event with routine change compared to only 6 (12%) dementia controls. This gives a relative risk of admission after a routine change life event as:

$$\text{Relative risk } \psi = \frac{30 \times 44}{40 \times 6} = 5.50 \pm 0.98 \text{ (95\% CI)}$$

This suggests that dementia sufferers who experience routine change life events were between 4.5 time and 6.5 times more likely to be admitted than those who had not experienced such events.

### Life events, severity of threat and routine change

Table 4.3.8D shows how degree of routine change varies with degree of threat. Out of the 206 events, 91 (44.2%) had severe (marked or moderate) threat and no routine change, whereas 56 (27.1%) had mild or no threat and no routine change. Fifteen events (7.3%) had some degree of routine change but mild or no threat and 44 (21.4%) had routine change and severe threat. Of the 135 severe events only 32.6% (44) had routine change. There was no significant association between severity of threat and routine change although there was a trend (Kendall's tau = 0.097, p = 0.056).

Table 4.3.8D Severity of threat compared to routine change in life events

TOTAL NUMBER OF LIFE EVENTS = 206		Severity of threat				
		None	Mild	Moderate	Marked	Any
Degree of Routine Change	None	1	55	55	36	147
	Mild	1	5	8	5	19
	Moderate	1	7	13	3	24
	Severe	0	1	7	6	14
	Extreme	0	0	0	2	2
	Any	3	68	83	52	206

In order to look at the potential combined effects of threat and routine change this section uses severe life events with some degree of routine change and the standard periods of 0-3 months, 4-6 months and 0-6 months. Once again the categories of

*independent* and *independent plus possibly independent* events were looked at for the three groups. Table 4.3.8E shows a higher number of patients having had one or more severe life events accompanied by a degree of routine change compared to either the dementia controls or fit elderly. For severe events the dementia patient group had a significantly increased rate for the 0-3 month ( $\chi^2 = 6.52$ ,  $p < 0.05$ ) and 0-6 month periods compared to the two control groups. For the 4-6 month period there was a significantly increased rate compared to the dementia controls (Fisher's,  $p = 0.01$ ). However, with the fit elderly the comparison just failed to reach significance at the 5% level (Fisher's,  $p = 0.06$ ).

Table 4.3.8E Subjects with one or more severe life events containing a change in routine in time period

		Dementia Patients	Dementia Controls	Fit Elderly
Severe	0-3 months	14/70 (20%)	3/50 (6%)	4/50 (8%)
	4-6 months	11/70 (17.7%)	3/50 (6%)	4/50 (8%)
	0-6 months	22/70 (31.4%)	5/50 (10%)	8/50 (16%)
Independent Severe	0-3 months	8/70 (11.4%)	2/50 (4%)	4/50 (8%)
	4-6 months	10/70 (14.3%)	1/50 (2%)	3/50 (6%)
	0-6 months	15/70 (21.4%)	3/50 (6%)	7/50 (14%)
Severe Independent and Possibly Independent	0-3 months	12/70 (17.1%)	2/50 (4%)	4/50 (8%)
	4-6 months	10/70 (14.3%)	2/50 (4%)	4/50 (8%)
	0-6 months	19/70 (27.1%)	4/50 (8%)	8/50 (16%)

Of the total number of severe events occurring in the six month period (before admission) for each group only a proportion had routine change. Altogether, 22 out of the 38 (57.9%) dementia patients with severe events, had severe events with routine



change. In contrast, only 5 out of 21 (23.8%) dementia controls and 8 out of 21 (38.1%) fit elderly who had severe events also experienced a degree of routine change as part of them. There was a significant excess of severe events with routine change in the dementia patients compared to the two control groups ( $\chi^2 = 6.76$ , 2 df,  $p = 0.034$ ).

The dementia patients had more independent severe events with routine change than the fit elderly (Fisher's,  $p = 0.21$ ) and the dementia controls (Fisher's  $p = 0.10$ ) for the period 0-3 months before admission; although neither of these results reached statistical significance. On the other hand, there was a significant difference for the 4-6 month period compared with the dementia controls (Fisher's,  $p = 0.02$ ) but there was only a trend compared with the fit elderly (Fisher's,  $p = 0.09$ ). For the 0-6 month period there was again a significant difference with the dementia controls ( $\chi^2 = 4.30$ ,  $p = 0.04$ ) but not for the fit elderly.

Independent and possibly independent severe threat events with some degree of routine change were significantly more common in the dementia patients compared to the dementia controls for 0-3 months (Fisher's,  $p = 0.02$ ), 4-6 months (Fisher's,  $p = 0.046$ ) and 0-6 months (Fisher's,  $p = 0.017$ ). The dementia patients still had more such life events with routine change than the fit elderly but this did not reach the 5% significance level for any of the three time periods of 0-3 months (Fisher's,  $p = 0.079$ ), 4-6 months (Fisher's,  $p = 0.136$ ) or 0-6 months (Fisher's,  $p = 0.223$ ).

The results suggest that the aspect of life events that disrupts the individual's routine leads to deteriorated functioning in dementia sufferers. It is also relevant to note that the dementia control group nearly always had significantly fewer such events than the dementia patients, and also fewer than the fit elderly. One possible reason for their apparent stability may have been a lack of routine disrupting life events. There may also be a tendency for dementia sufferers to have fewer life events or to have fewer reported. Having said this, only a minority of dementia patients suffered such events and in the remaining cases there must of course be other factors leading to admission.

#### **Life events before deterioration and change in routine**

In this analysis only the life events of the dementia patients who had a datable deterioration were compared with the two control groups. As in the earlier section life events over the previous three months were included and compared with life events in a corresponding time period for each of the control groups (the 4-6 month period prior to interview). In this three month period 9 out of 43 (21%) dementia patients had a life event with routine change, compared to 3 (6%) of the dementia controls (Fishers,  $p = 0.026$ ) and 5 (10%) of the fit controls ( $p = 0.081$ ). Despite the small numbers, the difference between the dementia patients and dementia controls remained significant when independent ( $p = 0.032$ ), and independent plus possibly independent ( $p = 0.022$ ) events with routine change were looked at. When only severe events were looked at the differences were no longer significant, although there was a general excess in the dementia patients and the results consistently suggested a trend for severe ( $p = 0.078$ ), severe independent ( $p = 0.083$ ), and severe independent plus possibly independent ( $p$

= 0.073) events. Although there was also an excess of events with routine change in the dementia patients compared to the fit controls, this did not reach significance.

### Life events and change in environment

In Table 4.3.8F the number of life events in the past six months with some element of environment change is shown for each group. A somewhat higher proportion of dementia patients had environment change associated with their life events compared to the two control groups. However, a lower proportion of events led to environment change than to routine change.

Table 4.3.8F Number of life events with environment change

Degree of environment change linked with life event	Dementia Patients	Dementia Controls	Fit Elderly
No change (0)	66	54	43
Mild change (1)	1	1	1
Moderate change (2)	10	2	1
Severe change (3)	6	5	0
Extreme change (4)	3	0	1
Life events with any environment change (1-4)	20 (23.3%)	7 (13.0%)	3 (6.5%)
Total life events	86	54	46

In this analysis there was a significant difference between the dementia patients and the fit elderly controls ( $\chi^2 = 4.73$ ,  $p = 0.03$ ), but not the dementia controls ( $\chi^2 = 1.64$ ,  $p = 0.20$ ). There was also no difference between the dementia controls and fit elderly



controls (Fisher's,  $p = 0.15$ ). There appear to be clear trends towards more life events with environment change in the dementia patient group but the small numbers make a significant result less likely.

The next analysis of life events with environment change looked at subjects with one or more life events with any degree of threat and various degrees of independence. All levels of severity of threat were included since it was considered possible that disruption to the dementia sufferer's perceptual environment might be difficult for the individual to adapt to, whatever the level of threat occasioned by the event. The comparisons in Table 4.3.8G show that as with routine change, environment change occurred far more often in the dementia patient group compared to the two control groups, particularly for the period 0-3 months before admission.

Table 4.3.8G Subjects with one or more life events containing a change in environment in the time period (before admission).

		Dementia Patients	Dementia Controls	Fit Elderly
All	0-3 months	12/70 (17.1 %)	3/50 (6%)	1/50 (2%)
	4-6 months	6/70 (8.6%)	4/50 (8%)	2/50 (4%)
	0-6 months	18/70 (25.7%)	6/50 (12%)	3/50 (6%)
All Independent	0-3 months	5/70 (7.1%)	1/50 (2%)	1/50 (2%)
	4-6 months	3/70 (4.3%)	3/50 (6%)	1/50 (2%)
	0-6 months	8/70 (11.4%)	4/50 (8%)	2/50 (4%)
All Independent and Possibly Independent	0-3 months	8/70 (11.4%)	1/50 (2%)	1/50 (2%)
	4-6 months	5/70 (7.1%)	4/50 (8%)	2/50 (4%)
	0-6 months	13/70 (18.6%)	5/50 (10%)	3/50 (6%)

Because of the small numbers of subjects with environment change the probability of a type II statistical error was high. However, taking all events in the 0-6 month period, the dementia patients had experienced significantly more life events with environment change than the other two groups ( $\chi^2 = 9.28$ ,  $p < 0.01$ ). This was also true for the 0-3 month period comparing dementia patients to dementia controls (Fisher's,  $p = 0.044$ ) and fit elderly controls (Fisher's,  $p = 0.006$ ). It appears from these results that the period 0-3 months before admission is most influential.

For independent events with environment change there were no significant associations for any time periods but the comparison between dementia patients and fit elderly came close (Fisher's,  $p < 0.1$ ).

Looking at independent plus possibly independent events, dementia patients had experienced significantly more with environment change than either control group (Fisher's,  $p = 0.045$ ) in the 0-3 month period. In the 0-6 month period dementia patients had significantly more than the fit elderly (Fisher's,  $p = 0.030$ ) but not significantly more than the dementia controls (Fisher's,  $p = 0.093$ ).

Taken as a whole the results suggest that life events with environmental change were more common in the dementia patient group. This indicates that environmental change life events in the three months before admission may lead to deterioration in mental state or coping capacities and so potentially precipitate admissions.



### **Relative risk of admission after environment change life event**

The relative risk (odds ratio) and confidence intervals (CI) were calculated for life events with environment change over the 0-3 month period before admission. Twelve (17%) dementia patients had an environment change life event compared to only 3 (6%) dementia controls. This gives a relative risk of admission after an environment change life event as:

$$\text{Relative risk } \psi = \frac{12 \times 47}{58 \times 3} = 3.24 \pm 0.45 \text{ (95\% CI)}$$

This suggests that environment change life events increases the relative risk of being admitted for dementia sufferers between 2.8 and 3.7 times.

### **Life events, severity of threat and environment change**

In Table 4.3.8H degree of environment change is compared with degree of threat for each life event. Out of the 206 events, 112 (54.4%) had severe threat and no environment change, and 57 (27.7%) had mild or no threat and no environment change. Fourteen events (6.8%) had some degree of environment change but mild or no threat and 23 (11.2%) had environment change and severe threat. Of the 135 severe events only 17% (23) had environment change. There was no significant association between severity of threat and environment change (Kendall tau = - 0.048, p = 0.24).

Table 4.3.8I shows the number of subjects with independent severe, and independent plus possibly independent severe life events that also had a component of environment change. None of the results of the analysis comparing the dementia patients with the other two groups show any significant difference. However, in all categories the



dementia patient group had a higher rate of such life events, suggesting a trend towards significance. It may be that because of the small numbers involved there are not enough subjects with environment change to illustrate whether or not a real difference does exist.

Table 4.3.8H Severity of threat compared to environment change in life events

TOTAL NUMBER OF LIFE EVENTS = 206		Severity of threat				
		None	Mild	Moderate	Marked	Any
Degree of Environment Change	None	1	56	67	45	169
	Mild	1	3	0	0	4
	Moderate	1	3	10	2	16
	Severe	0	6	4	3	13
	Extreme	0	0	2	2	4
	Any	3	68	83	52	206

In the 0-6 month period for severe life events the results approached significance but only compared to the fit elderly controls (Fisher's,  $p = 0.07$ ). Comparing severe independent plus possibly independent events over the six month period there was also an excess of events in the dementia patients over the fit elderly controls (Fisher's,  $p < 0.1$ ). Likewise, in the analysis of severe independent, and severe independent plus possibly independent life events, none of the results reached significance. This suggests

that if there is a contribution of environment change related to severe life events before admission this is not important in the majority of admissions of dementia sufferers.

Table 4.38I Subjects with one or more severe life events containing a change in environment in time period

		Dementia Patients	Dementia Controls	Fit Elderly
Severe	0-3 months	6/70 (8.6%)	3/50 (6%)	1/50 (2%)
	4-6 months	4/70 (5.7%)	3/50 (6%)	1/50 (2%)
	0-6 months	10/70 (14.3%)	5/50 (10%)	2/50 (4%)
Independent Severe	0-3 months	3/70 (4.3%)	1/50 (2%)	1/50 (2%)
	4-6 months	2/70 (2.9%)	2/50 (4%)	0/50
	0-6 months	5/70 (7.1%)	3/50 (6%)	1/50 (2%)
All Independent and Possibly Independent	0-3 months	5/70 (7.1%)	1/50 (2%)	1/50 (2%)
	4-6 months	3/70 (4.3%)	3/50 (6%)	1/50 (2%)
	0-6 months	8/70 (11.4%)	4/50 (8%)	2/50 (4%)

Less than a third of the total number of severe life events occurring in the six month period (before admission) for each group had environment change. Altogether, 12 out of the 38 (31.6%) dementia patients with severe life events, had severe life events with environment change; whereas only 5 out of 21 (23.8%) dementia controls and 2 out of 21 (9.5%) fit elderly controls who had severe life events also experienced a degree of environment change as part of them. The dementia patients had significantly more severe life events with environment change compared to the fit controls (Fisher's,  $p = 0.043$ ) but not compared to the dementia controls (Fisher's,  $p = 0.20$ ).



### **Life events before deterioration and change in environment**

Life events with environment change in the three months before deterioration in the dementia patients were compared with life events occurring in a similar period for the two control groups. As with routine there was a general excess of subjects with environment change life events in the dementia patients compared to the two control groups. Eight (18.6%) dementia patients had life events with environment change compared to only 4 (8%) dementia controls and 2 (4%) fit elderly controls. There was a significant difference between the dementia patients and fit elderly controls (Fishers,  $p = 0.022$ ) but not with the dementia controls ( $p = 0.080$ ). No other comparisons (including threat and independence dimensions) were significant. However, there were clear trends towards the dementia patients having more environment change life events than each of the control groups. With such small numbers with life events there is an obvious danger of a type II statistical error.

### **Life events and the social environment**

The results of the analyses of change in the social environment (whether routine and environment) life events before admission and deterioration indicate that the addition of the severe threat component does not contribute to the difference between the groups. This may be partly because of the smaller numbers involved. However, another implication could be that social environment change is more important than the threat of a life event in its capacity to disrupt the functioning and coping skills of the dementia sufferer. In this way social environment change events significantly increase the risks of deterioration and also admission. Overall, it can be argued that, for dementia sufferers, life events which are stressful in terms of *threat* lead to



depressive symptoms whereas life events which are stressful in terms of *social environment* change lead to deterioration and admission.

### **Logistic regression analysis with routine and environment**

In order to look at the relative effects of routine and environment on the differentiation between the groups of dementia patients and dementia controls, a logistic regression analysis was done using group membership as the dependent variable. The independent variables included: age, sex, depressive symptoms, severity of dementia (GMSS), CAPE, acute deterioration score, and an additional independent variable chosen from the routine and environment categories listed below. The analysis was repeated for each of these eight categories of life events:

■ Life events with routine change in the 0-6 month period before admission and the three months before deterioration

■ Independent life events with routine change in the 0-6 month period before admission and the three months before deterioration

■ Life events with environment change in the 0-3 months before admission and 0-3 months before deterioration

■ Independent life events with environment change in the 0-3 months before admission and 0-3 months before deterioration

As before, severity of dementia and age were removed from the analysis and CAPE score and acute deterioration score were highly associated with the dementia patient group. Life events with routine change over the 0-6 months before admission also predicted membership of the dementia patient group as shown in Table 4.3.8J.

**Table 4.3.8J Result of logistic regression analysis looking at factors which differentiate between two dementia groups**

----- Model if Term Removed -----				
	Log			Significance
	Likelihood	-2 Log LR	df	of Log LR
Routine life events	-52.35	8.17	1	.0043
CAPE	-53.47	10.42	1	.0012
Deterioration score	-73.12	49.71	1	.0000

Considering the very high significance level ( $p = 0.0043$ ), life events with routine change appear to be very strongly associated with admission. This result was maintained when independent life events with routine change were included ( $p = 0.006$ ).

The analysis was repeated, entering life events with routine change *before* deterioration ( $p = 0.098$ ), and then again, using only independent ones ( $p = 0.035$ ). When other variables are taken into account, independent life events with routine change remained highly associated with admission and deterioration. This suggests that such life events may precipitate both deterioration and admission.

For the next set of analyses, environment change life events in the three months before admission were entered in place of those with routine change; and they did not differentiate between the two dementia groups. However, there was a trend ( $p = 0.058$ ) if degree of independence was not taken into consideration. When life events before deterioration were analysed, there were no significant associations with dementia group.

### **Depressive symptoms and change in environment or routine**

This analysis sought to identify whether it was the component of change in routine associated with life events that led to depressive symptoms in dementia sufferers. In this analysis, the presence or absence of depressive symptoms was therefore the dependent variable. The independent variables were age, sex and group together with events characterised by routine and environment change as in the previous sets of analyses. The results showed only age ( $p = 0.032$ ) to be significantly associated with depressive symptoms in dementia sufferers, since all the other variables were eliminated by the forward stepwise procedure. Independent routine change life events in the 0-6 months before admission was the last variable to be eliminated ( $p = 0.117$ ). Thus, independent life events with routine change *may* have a role in the precipitation of depressive symptoms in dementia sufferers. However, the earlier analyses indicate that it is the degree of threat that is the crucial factor in precipitating depressive symptoms.



#### ***4.4.0 Factors affecting admission and doctor's awareness of life events***

In order to ascertain the reliability of the acute deterioration score and examine the factors leading to admission, a study of correspondence after assessment was done. It comprised two sets of letters as described in the method section 3.3.0. The raters also noted life events in the correspondence. This enabled an assessment to be made of the relative influence of knowledge of the patient's life events by the referrer and the assessing psychiatrist, on the decision to arrange admission.

(A) 50 letters prior to admission for the dementia patients

(B) 80 letters following domiciliary visits

One rater (Martin Orrell) rated only letters from group (B) whereas the other (Dominic Lam) rated letters from both groups (A) and (B). The raters scrutinised the letters and rated them on a number of physical, psychological and social factors as well as using the acute deterioration scale. All the letters had been edited to remove details of their source, identity and whether or not the subject had been admitted. This was to ensure that rater DL could not discriminate between the two groups and would therefore be blind to the awareness of admission.

In addition the letters were also rated for the presence of life events to see if knowledge of life events had influenced the referrer's decision whether or not to seek admission. For the purposes of the analysis the results will be split into the two groups (A) and (B).

### **Reliability of ratings between two raters**

The results of group (B) were subjected to a computer program for assessing inter-rater reliability which uses weighted KAPPA (Cicchetti, 1976). This statistic is widely accepted for assessing reliability because it is distribution free and allows credit for partial agreement (Cohen, 1968; Hall, 1974). The problems of a high level of agreement but a low KAPPA have recently been discussed (Feinstein and Cicchetti, 1990; Cicchetti and Feinstein, 1990).

The rating methods, guidelines, and coding sheets used were essentially the same as those used in the main Life Events in Senile Dementia study, although some minor adaptations were needed.

The key variables which were tested for reliability were:

- 1) Presence and degree of current physical illness
- 2) Assessment of acute deterioration
- 3) Presence and severity of life events
- 4) Presence and degree of physical disability
- 5) Likelihood of admission.

These variables were chosen because on the one hand they seemed most susceptible to inter-rater variability (in comparison with variables such as history of psychiatric admission - yes or no) and on the other hand it was an important objective of the study to test variables for reliability between raters. Table 4.4.0A shows the levels of agreement and KAPPA values for the measures evaluated.

**Table 4.4.0A KAPPA levels and levels of agreement between two raters (DL and MO) for specified variables**

	Observed Agreement	Expected Agreement	KAPPA
<u>Current physical illness</u>			
Cardiovascular	.97	.94	.51
Respiratory	.99	.99	.66
Neurological	.93	.84	.57
Neoplastic	No cases		
Metabolic/Endocrine	.98	.98	.32
Infection	.98	.98	.32
Bone/Joint/Muscle	.94	.91	.30
<u>Physical disability</u>	.95	.76	.41
<u>Acute deterioration</u>			
Irritable/Suspicious	.88	.76	.52
Depressed/Withdrawn	.90	.64	.73
Wandering/Restless	.85	.68	.55
Aggressive/disinhibited	.86	.74	.48
Cognitive decline	.83	.52	.64
Self care	.83	.58	.60
Sleep problems	.92	.70	.74
Incontinence	.95	.80	.77
Other problems	.71	.57	.32
<u>Risk of admission</u>	.77	.64	.37
<u>Life Events</u>	.94	.69	.80

Table 4.4.0A shows that the level of agreement for most variables is relatively high at more than 0.9 for all physical illness/disability scores and life events, over 0.8 for aspects of acute deterioration (except 0.71 for 'other problems') and 0.77 for the probability of admission.

The KAPPA values for the physical illness variables are relatively good for cardiovascular, respiratory and neurological scores and poor for the other variables in



this group. The principle problem here concerns the way KAPPA is calculated (Feinstein and Cicchetti, 1990; Cicchetti and Feinstein, 1990) for these groups which have high levels of *observed agreement* but because of a low number of subjects with problems in each of the categories they also have very high levels of *expected agreement*. The low number of subjects with problems means that using this method the observed agreement must be exceptionally high in order to achieve a 'good' KAPPA value of 0.6, or an excellent KAPPA of 0.8 or more. Considering the needs of this particular study the values of KAPPA for cardiovascular, respiratory, and neurological disorders are remarkably good considering that the source of the information is unstandardised letters. In the main study the full medical notes, patient's and informant's reports and discussion with medical and nursing staff were used to get a more accurate idea of the prevalence of physical disorders. Ratings based on such wide sources are likely to be considerably more accurate but not necessarily more reliable since more sources for information can give more opportunities for disagreement.

The KAPPA values for the acute deterioration variables are generally much better and all over 0.5 except for 'aggressive/disinhibited behaviour' (0.48) and other problems (0.32). As the 'other problems' category covered everything else, there was far more scope for interpretation about what should be included and how it should be scored. It is less clear why the 'aggressive/disinhibited' variable was interpreted differently by the raters. What constituted aggressive or disinhibited behaviour should probably have been more clearly discussed and defined by the raters prior to the rating exercise. The

best agreement was for incontinence, sleep problems, depressive or withdrawn symptoms, and cognitive decline.

For life events the agreement was also very good at 0.8. During the pilot of this part of the study there were some difficulties agreeing on what constituted a life event. Further discussion and clarification after the pilot study appears to have resulted in better agreement between the raters in the main study.

There was a low level of agreement between the two raters as to whether or not the person should be admitted. This may mean that there are important differences between the raters in terms of their attitudes towards the use of admission and might in some way reflect their training (psychiatry versus clinical psychology), experience and background. On the other hand it may be that predicting admission is very difficult to do consistently and this study may have illustrated this.

### **Population characteristics**

The characteristics of Group A have been described in detail in section 4.31-4.37. Group B will therefore be described in this section. Results refer to DL's data, (although MO independently repeated ratings).

Of the 80 in Group B, 25 (31.3%) were male and 55 (68.8%) female. In three age groups: 20 (23.8%) were aged 60-74, 44 (55%) aged 75-84, and 16 (20%) aged 84-98.

In terms of diagnosis (as specified in the letter) 46 of the 80 (57.5%) patients had senile dementia, 13 depression, 0 mania, 1 schizophrenia/paraphrenia, 2 delirium, 1 alcohol dependence, 1 'life situation reaction', 1 was well and 15 had no diagnosis specified.

#### **Prediction of admission: Group A**

The following analyses looking at predictability of admission (based on the review of correspondence) provides an insight into the decision-making process. In Group (A) 49 out of 50 had adequate information. All of the group were admitted but some were not admitted directly after or as a result of the letter rated by DL. Four of the 49 were rated as 'don't know' by DL as to whether the person would be admitted as a result of the letter, of these 2 were directly admitted and 2 people's admissions were not directly as a result of the letter.

This left 45 patients who were admitted which DL had attempted to classify into 'admission likely' and 'admission unlikely' groups. DL classified 35 of the 45 correctly (77.8%) (admission likely) and these patients were directly admitted. However of the 10 incorrectly classified (admission unlikely), 8 had a delay before admission, suggesting that in many cases DL's prediction of 'admission unlikely' may have been a reasonable judgement.

#### **Prediction of admission: Group B**

This Group (B) consisted of 80 assessment letters about patients seen on domiciliary visits. The patients were either classified into admitted or not admitted (unlike group



A where all the patients were admitted eventually but not necessarily as a direct result of the letter evaluated). 31 of this group were admitted and 49 not admitted. Table 4.4.0B shows the rate of successful prediction of admission comparing the two raters.

**Table 4.4.0B Prediction of admission by the two raters**

	<u>Admitted</u>	<u>Not admitted</u>
<u>Rater DL</u>		
Admission likely	21/31	14/49
Don't know	1/31	4/49
Admission unlikely	9/31	31/49
<u>Rater MO</u>		
Admission likely	20/31	16/49
Don't know	4/31	3/49
Admission unlikely	7/31	30/49

Comparing the results in Table 4.4.0B excluding the don't knows, DL correctly classified 21 of 30 admissions (specificity, 70%), and 31 of 49 non admissions (sensitivity, 68.8%), giving an overall agreement of 69.3%. Rater MO classified 7 as don't know. Excluding the don't knows MO correctly classified 20 of 27 (specificity, 74.1%) admissions and 30 of 46 (sensitivity, 65.2%) non admissions, giving an overall agreement of 68.5%.

This result suggests that it is possible to predict with around a 70% accuracy those patients who will be admitted to hospital from an analysis of the psychiatrist's letter, even when details such as the decision-making process and treatment options have been specifically deleted. This suggests that the process of decision-making might be similar even when based on such variable data as correspondence. However from the results of KAPPA there is a degree of inconsistency between the raters.

The higher rate of prediction of admission for group A (from the Life Events in Senile Dementia study) may reflect a clearer or more straightforward decision-making process for professionals assessing patients with dementia. To investigate whether or not diagnosis was important in effecting the accuracy of the predictions of admission a further analysis was performed using Group B and comparing prediction of admission with diagnosis.

However looking at the 46 patients with dementia in group B, DL classified 3 as 'don't know' with respect to admission. Out of the admissions DL predicted 11 of 16 correctly (73.3%) and 18 out of 28 of the non admissions (64.3%). This gave an overall correct prediction rate of 67.4% (29 of 43). MO classified 5 as 'don't know' with respect to admission. Out of the remaining patients MO correctly predicted 10 of 13 (76.5%) as admitted and 16 of 28 as not admitted (57.1%) as result of the letter. This gave MO an overall correct prediction rate of 63.4% (26 of 41).

These results suggest that the raters were slightly better at predicting admissions for patients with senile dementia compared to non admissions but overall there is very little difference. They also tended to err on the cautious side in favour of admission in some cases.

#### **Acute deterioration score and admission.**

For Group B there was a high correlation between the total acute deterioration scores of the two raters (correlation = 0.70,  $p < 0.001$ ) but MO tended to score higher with a mean of 7.69, compared to a mean of 5.93 for DL.

The raters were also asked to predict the likelihood of admission on a five point scale (very likely, fairly likely, don't know, fairly unlikely, very unlikely). The correlation between increased acute deterioration score and increased likelihood that the raters predicted the admission was 0.64 ( $p < 0.001$ ) for MO and 0.31 for DL ( $p < 0.01$ ). This means there is a significant relationship between high deterioration score and predicted decision to admit for both the raters, and indicates that the deterioration index has some validity in terms of prediction of admission.

When the relationship between actual admission and acute deterioration score was investigated using the t-test there was no significant relationship (for DL:  $t = 1.37$ ,  $p = 0.173$ ; for MO  $t = 1.20$ ,  $p = 0.234$ ). This suggests that the deterioration score alone was not a good predictor of admission, although for both raters the mean score in those admitted was higher than in those not admitted and it may be that the raters considered the overall level of symptoms in making their judgement about admission.



### **Life events and admission**

For Group A from the analysis of the letter DL was able to identify 7 (9.86%) life events out of the total of 71 life events (from 49 the cases taken from the main Life Events in Senile Dementia study). Psychiatric assessments (such as home visits) would be expected to include enquiry about life events and include details in the letter to the general practitioner. This indicates that the doctors involved in the admission process were probably unaware of the vast majority of life events. This suggests that knowledge of life events could not have been a significant factor in the doctor's decision to admit. It is possible that some doctors did not mention life events which they were aware of in the letter or that at the time of interview they did not have access to an informant who could give them an adequate life events history.

In addition, in Group B, 8 out of 31 (25.81%) admitted patients and 6 of 49 (12.24%) non-admitted patients had threatening life events noted by DL in the letter. There is no significant difference between these two groups ( $\chi^2 = 1.43$ ,  $p = 0.23$ ). Although there appears to be a trend towards life events being associated with admission, merely reviewing letters is probably not a satisfactory method of obtaining an adequate life event history.

This suggests that the doctors involved in assessment are probably unaware of the great majority of life events. These two analyses indicate that life events per se are not a significant factor in the decision-making process to admit an elderly patient with psychiatric problems such as dementia. This finding is also supported by the next section which investigates the factors leading to an admission.

### **Factors leading to decision to admit**

In order to further investigate the decision-making process and the possible contribution of a knowledge of life events, the two raters were asked to rate in order of priority the three main reasons they thought a decision to admit was made in those patients who they rated as 'admission fairly likely' and 'admission very likely'. In addition, the original unedited letters were later reviewed by MO to extract the details of the letter writer's reasons for admission.

Looking at Groups A and B combined (Table 4.4.1B) the original letter writer (several different doctors) tended to specify fewer than three reasons for admission (day patient or inpatient). 70 out of 71 cases admitted directly from the letter could be assigned one or more reasons for admission on the basis of the writer's reasons. The 'other' reasons mentioned in Table 4.41B included poor housing, need for assessment of placement, occupational therapy and rehabilitation, and organisation of other services. *Life events were not mentioned by any referrer as a contributory reason to the decision to admit.*

**Table 4.4.1B Factors leading to admission - specified by letter writer (130 cases)**

<u>Number of times</u>		<u>Factors - letter writer</u>
1st reason	Any reason (inc. 1st)	
38	52	Need for observation and assessment of mental state
17	23	Need for investigations
5	18	Need for treatment
3	15	Respite
3	12	Assessment of self care
3	5	Behavioural disturbance
0	1	Assessment of safety/need for safe environment
0	2	Risk of suicide
1	6	Other

Of the total 130 patients in Group A and Group B combined, DL judged admission as likely in 73. Compiling the responses from the three main reasons given, DL cited the following as his reasons for the most likely causes of admission (Table 4.4.1C)

**Table 4.4.1C Factors leading to admission - rater DL (130 cases)**

<u>Number of times</u>		<u>Factors (DL)</u>
1st reason	Any reason (inc. 1st)	
28	52	Need for observation and assessment of mental state
13	19	Need for investigations
7	32	Need for treatment
3	17	Respite
2	9	Assessment of self care
15	19	Behavioural disturbance
1	8	Assessment of safety/need for safe environment
3	3	Risk of suicide
1	13	Other

Of the total 80 patients in Group B only, MO judged admission as likely in 38. Compiling the responses from the three main reasons given cited the following reasons as likely causes of admission as shown in Table 4.4.1D.

**Table 4.4.1D Factors leading to admission rater MO (80 cases)**

<u>Number of times</u>		<u>Factors (MO)</u>
1st reason	Any reason (inc. 1st)	
9	27	Need for observation and assessment of mental state
2	9	Need for investigations
2	11	Need for treatment
0	3	Respite
5	15	Assessment of self care
19	24	Behavioural disturbance
0	7	Assessment of safety/need for safe environment
0	4	Risk of suicide
1	6	Other



The two raters identified a similar pattern of factors leading to admission, with need for assessment, behavioural disturbance and need for treatment being the main ones. For rater DL respite was a common reason but not the principal one. For rater MO assessment of self care was also mentioned frequently but not a principal reason. There may be overlap between some of the reasons (e.g. need for observation and assessment of mental state and behavioural disturbance which would also obviously require observation). The raters were asked to write in the reasons rather than choosing from a list, and so a proportion of reasons came under the category of 'other'. Reasons listed as other included malnutrition/not eating/weight loss, assessment of continence, treatment of alcohol problem and sleep problems. On only one occasion a life event was mentioned (by MO) as a contributory factor towards admission.

In conclusion, life events do not appear to be a component of the referrer's decision-making process to admit which is more influenced by other clinical factors.

### ***4.5.1 Follow up - Prognosis of dementia***

The first 60 patients from the Life Events in Senile Dementia study were followed up from two to three years later, and adequate data were obtained in all cases. These were defined as continuous details on the person's whereabouts and use of services during the follow-up period; details of any psychiatric or other hospital admissions and major illnesses; nursing home and residential care; use of specialist day centres and current condition or date and cause of death (if known). The last 10 patients were not followed up because the date of initial assessment was too recent for the minimum follow-up period of two years to have elapsed. The length of follow-up period was defined as the final date when all the follow up details (for the individual patient) were collected, less the date of initial admission. The average follow-up period was 34.9 months and there was no difference between the subgroups of those alive (35.0 months), and those who had died (34.9 months).

In the follow-up period no patients had more than:

- 1) Four psychiatric admissions (inclusive of index admission in full study)
- 2) Two medical admissions
- 3) Two nursing home admissions
- 4) Two residential home admissions
- 5) Two periods of day centre attendance

The length of each admission or attendance was calculated, and the total period of time in each type of service was worked out. In addition, the pathways through different types of care could be plotted for each individual.

## **Mortality**

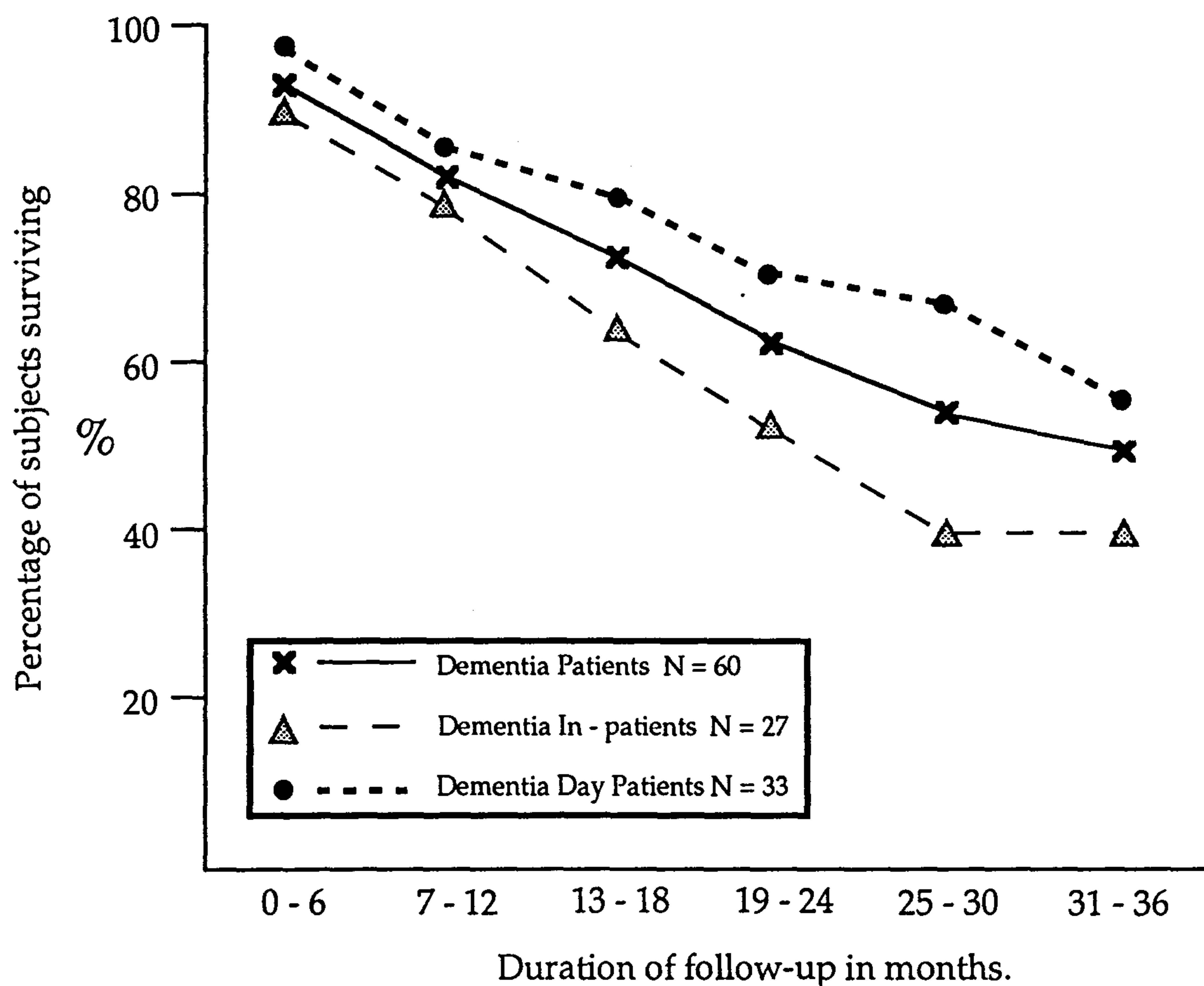
At follow-up 31 (51.7%) patients were alive, and 29 (48.3%) dead. The mean life span of those who had died was 15.9 months (standard deviation 8.6 months). The 50% survival rate was estimated as 36.1 months after entry to study, and the estimated five year survival rate was calculated as 17.2% (10.3 subjects). In order to see if past physical health had been significantly worse in those who had died, the physical problems scales were added to produce an overall measure of previous health. There was no significant association between survival at follow up and either past physical health ( $\chi^2 = 2.16$ ,  $p = 0.34$ ) or physical health at admission ( $\chi^2 = 1.30$ ,  $p = 0.52$ ). Thirteen out of the 33 (39.3%) who had initially been day patients were dead, compared to 16 out of 27 (59.3%) inpatients. Although the difference in death rate was 20% this was not significantly different ( $\chi^2 = 1.62$ ,  $p = 0.20$ ).

## **Survival analysis curves**

In order to look at survival over time, survival analytic methods were used (Armitage and Berry, 1987; Norušis/SPSSinc., 1990) to produce curves showing survival at sequential 6 month periods over the follow up. Figure 4.5.1A shows the differential survival of day patients and inpatients. Subjects who were initially admitted as day patients have a consistently better survival rate than the inpatients. When these two groups were compared using the Lee Desu statistic there was no significant difference ( $D = 2.858$ , 1 df,  $p = 0.091$ ) although the trend is clear.



**Figure 4.5.1A. Survival analysis of dementia patients with respect to initial admission.**



#### **Placement at follow-up**

Of the 31 patients alive at follow-up, 17 (54.8%) were in nursing homes, 11 (35.5%) were in residential homes, 2 (6.5%) were attending dementia day centres, and 1 (3.3%) was in continuing care psychiatric patient. In other words, only two were managing at home with the aid of community services, and the rest were in some form of long term institutional care.

### **Pathways through care**

Of the 27 who were inpatients at the start of the study 23 (85.2%) never went home, but instead continued in some form of institutional care. Day patients were significantly less likely to go on directly into institutional care after the end of their day patient admission with only 11 of 33 (33.3%) doing so ( $\chi^2 = 14.22$ ,  $p = 0.0002$ ). This indicates that there are far better prospects of continuing to live in the community after a day patient psychiatric admission compared to an inpatient one.

The pathways through care from admission to follow-up is shown for elderly dementia day hospital patients in Figure 4.5.1B and for inpatients in Figure 4.5.1C. The initial level of care after the first admission is shown followed by the route of each patient through care and their status at follow up. The prognosis of the day patients was far better, showing that a far higher proportion of them went on to community forms of support rather than institutional care, compared to the inpatients who nearly all remained in some form of institutional care after admission. The average length of stay for the initial psychiatric admission was 4.9 months for the whole group and 3 (5%) patients died during their initial inpatient admission.

Out of the 60 patients 36 (60%) had experienced some form of inpatient psychiatric care (including long stay) but only 4 (6.7%) had more than one such admission (discontinuous, i.e. not including direct transfers). Thirty-three (55%) had a previous psychiatric day hospital admission, and 6 (10%) had more than one separate admission.

Figure 4.5.1B Pathways through care of psychiatric day patients to follow-up

Follow  
Up

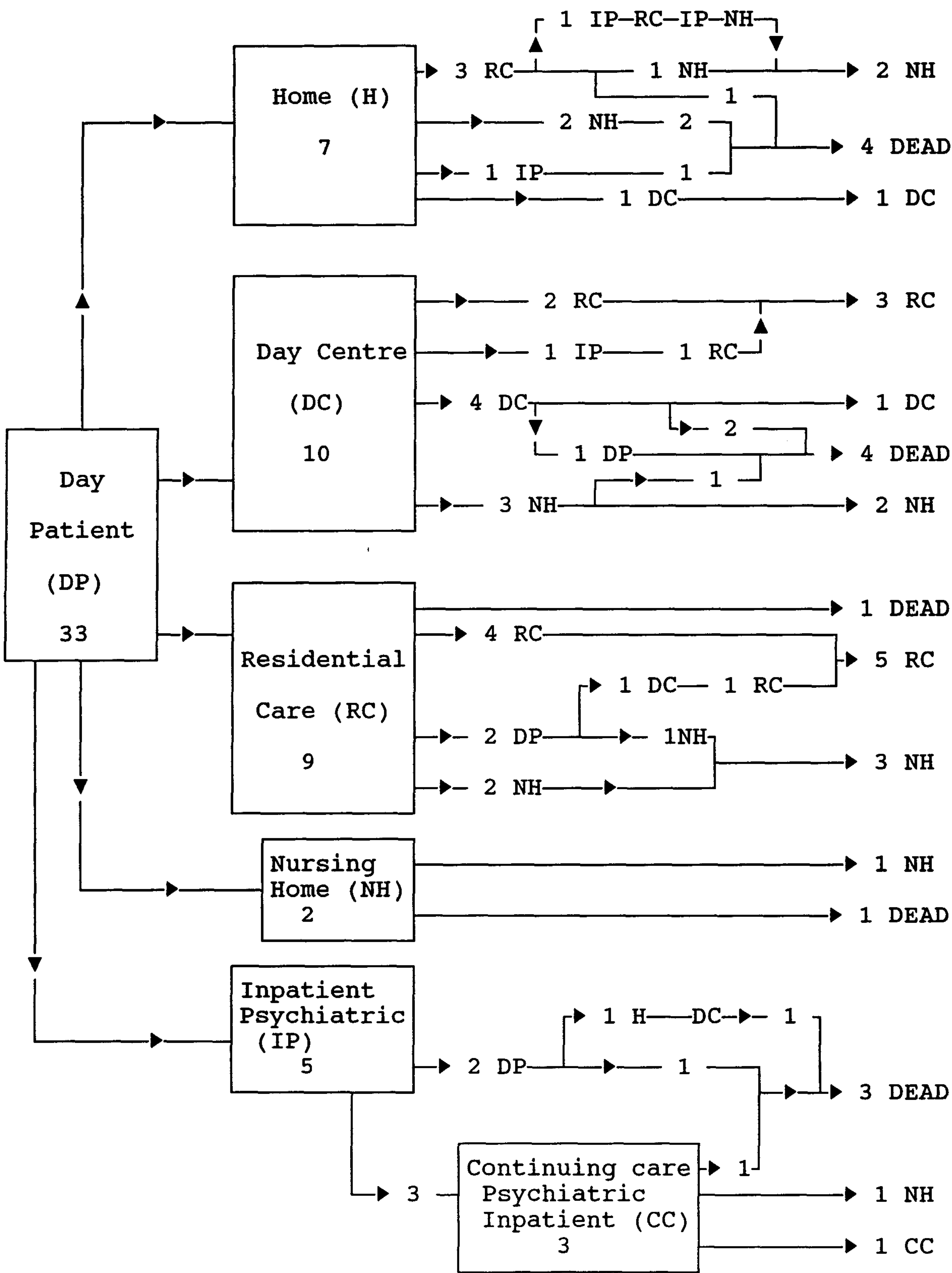
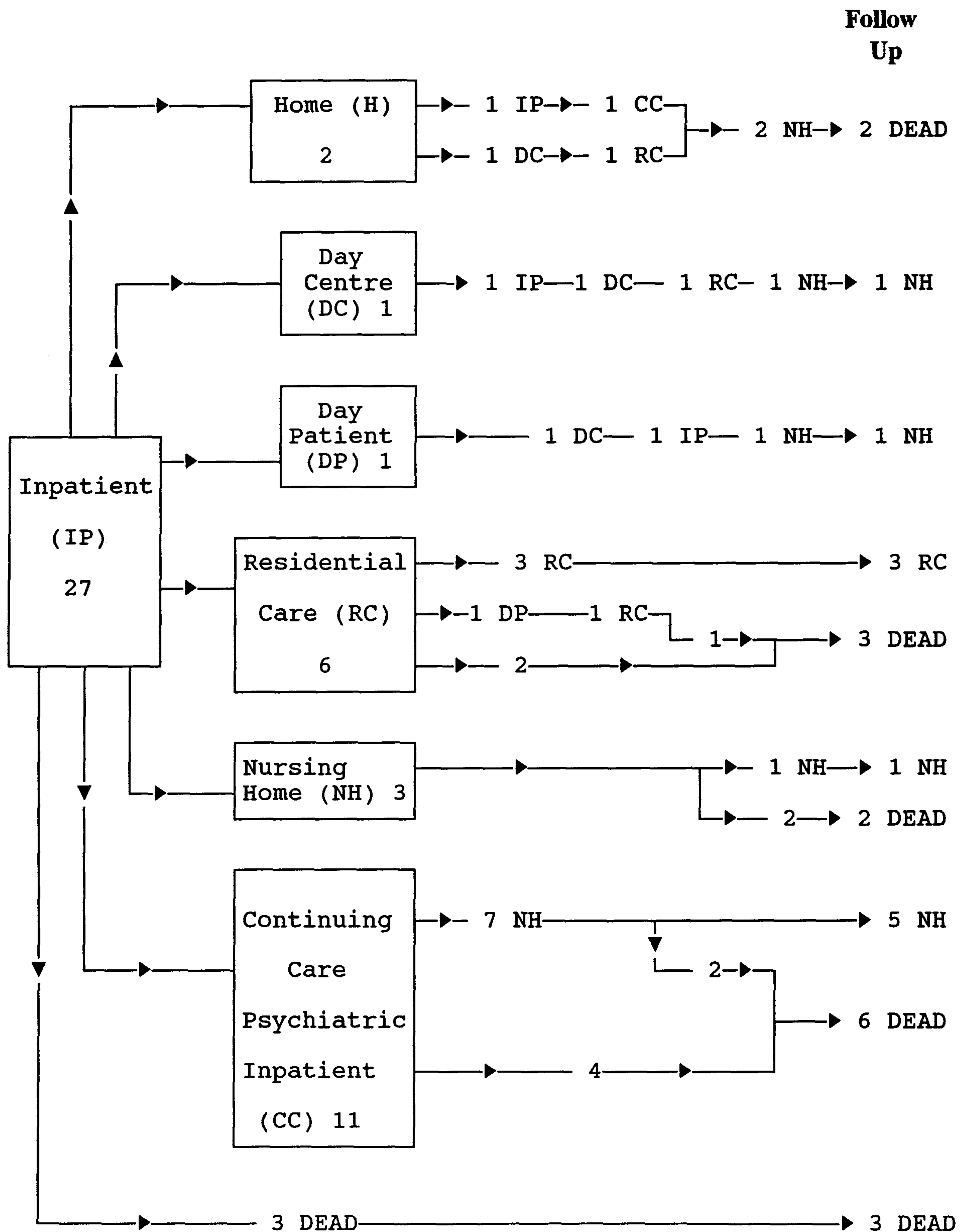




Figure 4.5.1C Pathways through care of psychiatric inpatients to follow-up



Twenty eight (46.7%) had at least one admission to a nursing home. Three patients were recorded as having had 2 admissions. One of these 3 patients actually moved to another nursing home whereas the other 2 were readmissions to the same nursing home after the patient had been admitted to a medical ward. Twenty four (40%) had at least one admission to residential care, and 6 had more than one admission. Only 2 of these were readmissions; the rest were transfers to and from hospital beds or other residential homes. A total of 19 (31.2%) had at least one period of attendance at a dementia day centre and of these, 3 had two separate periods of attendance.

### **Medical problems**

There was no significant association between status of initial admission (inpatient or day patient) and either past physical health ( $\chi^2 = 1.12$ ,  $p = 0.56$ ) or current health at initial admission ( $\chi^2 = 0.39$ ,  $p = 0.82$ ). In the follow up period, 15 patients had one or more episodes of severe physical illness (including a medical admission). These included: 6 episodes of stroke, 4 of pneumonia, 1 of heart failure, 1 of myocardial infarction, 2 fractured neck of femur, and 7 episodes of 'other' disorders.

### **Cause of death**

In 13 patients the cause of death was given as: 6 pneumonia, 2 heart failure, 1 myocardial infarction, 2 stroke, 1 cancer, 1 septicaemia. As the death certificates were not obtained in many cases it was not possible to have complete data on the cause of death for 16 out of 29 patients. From these data it is clearly wrong to generalise about the causes of death in the elderly population with senile dementia.

### Use of services according to type of admission and current status

Table 4.5.1A shows the average number of months of a particular service which patients used according to the status of their initial admission (day patient or inpatient), while Table 4.5.1B relates service to current status (survival). It is evident from Tables 4.5.1A and 4.5.1B that the type of initial admission is a much more important determinant of service use over time than survival. This is surprising since one would expect those patients who lived longer to use significantly more institutional care than those who did not live so long.

Table 4.5.1A Dementia patients - months of service use compared to initial admission

TYPE OF CARE	ALL Mean months (standard deviation)	DAY PATIENTS Mean months (standard deviation)	INPATIENTS Mean months (standard deviation)	T-test and Probability
Psychiatric inpatient	5.21 (7.31)	1.86 (5.85)	9.31 (6.89)	t = 4.53 p = 0.000 **
Medical inpatient	0.39 (1.53)	0.69 (2.02)	0.17 (0.06)	t = -1.73 p = 0.09
Nursing home	4.82 (7.51)	4.53 (7.85)	5.19 (7.19)	t = 0.34 p = 0.74
Residential home	7.42 (11.62)	8.22 (11.72)	6.43 (11.63)	t = -0.59 p = 0.56
All Institutional Care	17.84 (12.96)	15.31 (13.23)	20.94 (12.17)	t = 1.70 p = 0.09
Institutional Care as % of survival	68.79% (36.40)	49.23% (35.83%)	92.64% (18.72%)	t = 4.96 p = 0.000**
Psychiatric Day Patient	2.85 (5.40)	4.94 (6.53)	0.29 (1.15)	t = -3.65 p = 0.001**
Dementia day centre attendance	4.20 (8.89)	6.58 (10.52)	1.28 (5.20)	t = 2.39 p = 0.02*
TOTAL	60	33	27	



As an indicator of overall prognosis distinct from survival the total period of time in institutional care was calculated by adding the individual totals of time spent as a psychiatric and medical inpatient together with the periods of time spent in nursing home or residential home care. This appears in Tables 4.5.1A and 4.5.1B titled 'institutional care'. However, since the longer people live the more time on average they will have spent in institutional care, this measure alone would be closely related to survival. Instead, a more useful measure would be the percentage of time spent in institutional care during the follow-up period (or until death). This is shown as 'institutional care as a % of survival'. This measure, which shows the percentage of time in institutions, allows the percentage of time spent being supported by community facilities to be defined.

Looking at Table 4.5.1A it is no surprise that day patients had more day patient (and day centre) care and inpatients had more inpatient psychiatric care, particularly as it has been shown that the great majority of inpatients continue in some form of institutional care. This has two implications: first, they are not likely to have the opportunity of day care since the majority are not discharged to the community, and second, as they are unlikely to be discharged home they may well spend several additional months in hospital until a suitable residential or nursing home facility has assessed and accepted them.

The inpatients probably had a shorter mean period of admission to medical wards not because they were healthier but because they were treated in the ward or other institution where they currently resided. This is supported by the numbers of people

who had medical admissions in each group: 12 (36.3%) day patients and 2 (7.4%) inpatients. It is also possible that a less aggressive approach to medical treatment is adopted in certain institutions caring for individuals with very severe dementia.

The most significant finding from Table 4.5.1A is that although day patients did not have a longer period in institutional care overall, in relation to survival day patients averaged 50.7% of their follow up period being supported at home by community services, whereas the corresponding figure for inpatients was only 7.4%.

Table 4.5.1B Dementia patients - months of service use compared to current status

TYPE OF CARE	ALL Mean months (standard deviation)	ALIVE Mean months (standard deviation)	DEAD Mean months (standard deviation)	T-test and Probability
Psychiatric inpatient	5.21 (7.31)	5.84 (8.68)	4.54 (5.55)	t = 0.69 p = 0.49
Medical inpatient	0.39 (1.53)	0.23 (0.50)	0.56 (2.14)	t = -0.84 p = 0.40
Nursing home	4.82 (7.50)	6.89 (8.83)	2.62 (5.04)	t = 2.28 p = 0.03*
Residential home	7.42 (11.62)	11.78 (13.50)	2.76 (6.76)	t = 3.24 p = 0.002*
Institutional Care	17.84 (12.96)	24.74 (10.47)	12.63 (8.62)	t = 5.08 p = 0.000**
Institutional Care as % of survival	68.79% (36.40%)	70.61% (32.88%)	66.80 (40.32)	t = 0.17 p = 0.49
Psychiatric Day Patient	2.85 (5.40%)	3.93 (6.94)	1.69 (2.67)	t = 1.63 p = 0.11
Dementia day centre attendance	4.20 (8.89)	7.10 (11.32)	1.09 (3.14)	t = 2.77 p = 0.008**
TOTAL	60	31	29	



Table 4.5.1B shows that there was no difference in the amount of psychiatric or medical inpatient care received by those still alive compared to those who had died. This is an important finding since increased psychiatric care should hopefully not be associated with an increased death rate. However, as expected (since they had lived longer) those who remained alive had more months of nursing home, residential or total institutional care and also day centre attendance compared to those who had died. But when controlling for the percentage of institutional care according to survival there was no difference between the two groups indicating that increased institutional care was not associated with a higher death rate in this sample.

#### ***4.5.2 Follow-up - prognosis, life events, clinical factors, and support***

Four principle indicators of prognosis were analysed in relation to life events, mental state, behavioural dependency (CAPE), deterioration and other social and support factors. The prognostic indicators were:-

- alive/dead at follow up
- length of survival
- length of time in institutional care
- percentage of survival in institutional care

##### **Prognosis and life events**

One of the principle aims of this part of the study was to examine the possible effects of life events (preceding admission) with prognosis. Subjects were divided into two groups according to whether or not they had experienced one or more severe independent life events. The two time periods selected were at 0-3 months and 0-6



months before the initial admission. For the time period 0-3 months before admission there was no difference in mortality for those with and without life events ( $\chi^2 = 0.21$ ,  $p = 0.65$ ). For the time period 0-6 months before admission 14 of the 26 (53.8%) who had a life event had died, whereas 15 of the 34 (44.1%) who had not had a life event had died. This was not a statistically significant difference ( $\chi^2 = 0.24$ ,  $p = 0.63$ ). Length of survival did not differ for groups with and without events in the 0-3 month ( $t = -0.22$ ,  $p = 0.83$ ) and 0-6 month ( $t = 0.33$ ,  $p = 0.75$ ) periods. There was no difference in amount of time spent in institutional care for the subgroups with and without life events for the 0-3 month ( $t = -0.36$ ,  $p = 0.72$ ) and 0-6 month ( $t = 0.65$ ,  $p = 0.52$ ) periods. And no difference in percentage of time spent in institutional care for these two subgroups for the 0-3 month ( $t = -0.15$ ,  $p = 0.88$ ) and 0-6 month ( $t = 0.47$ ,  $p = 0.64$ ) periods.

### **Prognosis and life events associated with routine and environment change**

In this part of the analysis, the dementia patient group was split into subgroups according to whether the subjects had experienced an independent life event with a component of routine change. There was no difference in mortality for life events with routine change in the 0-3 month period (Fisher's exact test,  $p = 0.54$ ) or in the 0-6 month period ( $\chi^2 = 0.20$ ,  $p = 0.65$ ) before admission. Length of survival did not differ (0-3 months,  $t = -1.03$ ,  $p = 0.31$ ; 0-6 months,  $t = -0.72$ ,  $p = 0.48$ ) periods. In addition, there was no difference in the length of time in institutional care (0-3 months,  $t = -0.61$ ,  $p = 0.55$ ; 0-6 months,  $t = 0.13$ ,  $p = 0.90$ ). Lastly, the percentage of time spent in institutional care did not differ (0-3 months,  $t = -0.70$ ,  $p = 0.49$ ; 0-6 months,  $t = 0.57$ ,  $p = 0.57$ ).

There was no association between mortality and the experience of independent environment change life events in either the 0-3 month (Fishers,  $p = 0.67$ ) or 0-6 month ( $\chi^2 = 0.54$ ,  $p = 0.46$ ) periods before admission. There was also no association between survival and environment change life events in the 0-3 month ( $t = -0.46$ ,  $p = 0.65$ ) or 0-6 month ( $t = -0.87$ ,  $p = 0.39$ ) periods. Nor was there an association found between length of institutionalisation and life events in the 0-3 month ( $t = -0.52$ ,  $p = 0.60$ ) and 0-6 month ( $t = -0.89$ ,  $p = 0.38$ ) periods. No relationship was found between percentage of survival in institutions and life events in the 0-3 month ( $t = -0.84$ ,  $p = 0.40$ ) and 0-6 month ( $t = -0.50$ ,  $p = 0.62$ ) periods.

These results suggest that the occurrence of life events (with or without routine or environment change) before admission does not effect mortality or the use of institutional care. However the numbers in some of the groups were quite small, and the possibility of a type II error cannot be excluded.

### **Prognosis and cognitive function**

Severity of cognitive impairment at initial assessment was compared with the four principle indicators of prognosis. There was no difference between severity of cognitive impairment and those who were alive at follow-up compared to those who were dead ( $t = -0.16$ ,  $p = 0.88$ ). Likewise there was no correlation between cognitive impairment and length of survival (correlation = 0.117), or, length of time (correlation = 0.098) and percentage of time (correlation = 0.001) in institutional care.



### **Prognosis and depressive symptoms**

Patients with and without depressive symptoms at initial assessment were compared to see if depressive symptoms predicted prognosis. Nine out of the 14 (64.3%) with depressive symptoms were dead at follow up compared to only 20 of the 46 (43.5%) without depressive symptoms but although there was a trend towards depressed subjects having a higher mortality, this difference was not significant ( $\chi^2 = 1.12$ ,  $p = 0.29$ ). Length of survival ( $t = 1.01$ ,  $p = 0.32$ ), length of time in institutional care ( $t = 0.12$ ,  $p = 0.90$ ), and percentage of time in institutional care ( $t = 0.17$ ,  $p = 0.86$ ) did not seem to be associated with having had depressive symptoms at initial assessment.

### **Prognosis and anxiety symptoms**

Patients with and without symptoms of anxiety at initial assessment were compared to see if anxiety symptoms predicted prognosis. 14 of the 20 (70%) with anxiety symptoms were dead at follow-up compared to only 14 of the 36 (38.9%) without anxiety symptoms and this trend was close to significance ( $\chi^2 = 3.12$ ,  $p = 0.08$ ). Likewise, length of survival ( $t = 1.01$ ,  $p = 0.32$ ) did not appear to be related to the subject having anxiety symptoms. Although length of time in institutional care ( $t = -1.22$ ,  $p = 0.23$ ) did not reach significance, percentage of time spent in institutional care ( $t = -2.04$ ,  $p = 0.047$ ) was significantly associated with the presence of anxiety symptoms at initial assessment. Patients with anxiety symptoms spent an average of 82.0% of their time in some form of institutional care compared to those without anxiety symptoms who had an average of 61.5% of their time in such care.



### **Prognosis and CAPE behavioural dependency score**

Length of survival did not appear to be closely related to the severity of dependency as measured by the total CAPE score. Although there was a small correlation (0.290) between an increased score and decreased length of survival this did not reach the level of a significant association. However, patients who had died by follow-up had a higher mean CAPE score of 15.8 at initial assessment compared to those who were still alive who had a mean CAPE score of 12.0. The t-test showed this to be a significant difference ( $t = 2.62$ ,  $p = 0.01$ ). Although there appeared to be no direct relationship between length of survival and CAPE score, this may be because the data were skewed since actual length of survival was only available for those who had died and not those who were still alive at follow-up. The correlations between CAPE score and length of institutional care was -0.079. The percentage of time alive in institutional care had a correlation with the CAPE score of 0.253. This suggests that although higher CAPE score is associated with a higher mortality, on the basis of these results the CAPE score may not be the most important factor influencing the length or likelihood of institutional care.

### **Prognosis and acute deterioration**

There was no significant association between the total score for acute deterioration and the length of survival (correlation = 0.064). In addition, the mean values of the acute deterioration score for those alive and those dead at follow up were almost the same at 9.69 and 9.93 respectively. This obviously did not support any relationship between mortality and deterioration score ( $t = 0.36$ ,  $p = 0.72$ ). There were small correlations between deterioration score and length of time in institutional care (0.230) and

percentage of survival in institutional care (0.275). This group of results suggests that acute deterioration score may affect prognosis, in terms of time spent in institutional care.

### **Prognosis and social class**

Since there had been slight differences in social class breakdown between the three groups in the main life events study, mortality was cross-tabulated against social class. However, there was no suggestion of any relationship ( $\chi^2 = 0.97$ ,  $p = 0.61$ ) and it therefore appeared fruitless to pursue further analysis.

### **Prognosis and family relationships**

In the full study, there were more communication difficulties between the key relative/informant and those in the dementia patient group compared to those in the dementia control group. This suggested that communication difficulties would be an important variable to examine in terms of the various indices of prognosis.

There was no relationship between mortality and severity of communication difficulties ( $\chi^2 = 0.11$ ,  $p = 0.74$ ). In addition there was no correlation between length of survival (correlation = -0.17), length of time in institutional care (correlation = 0.053), or percentage of survival spent in institutional care (correlation = 0.013).

This suggests that although communication difficulties may play a part in precipitating admission and/or acute deterioration they do not appear to influence prognosis overall.



### **Support, services and prognosis**

In order to look at the ways in which levels of support before admission may effect prognosis, the provision of meals on wheels, home help, day centre attendance and the involvement of relatives was compared for each of the various prognostic factors.

Eleven out of 14 (79%) persons receiving meals on wheels prior to admission had died compared to only 18 out of 46 (39%) for those with no service. There was a significant association between receiving meals on wheels prior to admission and higher mortality ( $\chi^2 = 5.20$ ,  $p = 0.023$ ). However there was no significant correlation between level of meals on wheels provision and length of survival (correlation = -0.268), length of institutional care (correlation = -0.190) or proportion of follow-up in institutional care (correlation = 0.043). For those receiving home help, 12 out of 23 (52%) had died compared to 17 out of 39 (44%) of those with no home help. This was not a significant difference ( $\chi^2 = 0.53$ ,  $p = 0.47$ ). There were also no significant correlation between level of home help provision and length of survival (correlation = -0.222), length of institutional care (correlation = -0.162), or proportion of follow-up in institutional care (correlation = 0.013).

Patients who had been attending a day centre two or more days per week prior to admission had a lower mortality with only 2 of 11 day centre attenders who had died (18%) compared to 27 out of 49 (55%) non-attenders who had died. This association showed a trend towards significance at the 5% level ( $\chi^2 = 3.54$ ,  $p = 0.060$ ). However, there was a highly significant correlation between frequency of day centre attendance prior to admission and increased duration of survival (correlation = 0.303,  $p = 0.01$ ),



but no association with length of institutional care (correlation = 0.222) or proportion of follow up in institutional care (correlation = 0.091).

Seven out of the 9 (78%) patients without relatives involvement had died compared to only 22 of the 51 (43%) who had help from relatives. There was a significant association between lack of relatives involvement and mortality (Fisher's test,  $p = 0.045$ ). However there were no correlations between degree of relatives involvement and length of survival (correlation = 0.002), length of institutional care (correlation = 0.086) or proportion of follow up in institutional care (correlation = 0.081).

#### **Factors associated with mortality**

In this analysis, the logistic regression method was used to identify which factors were associated with increased mortality, whilst controlling for other factors which may be important. The variables included standard demographic factors (such as age and sex), and also variables which appeared to differ between the two groups i.e. type of initial admission, severity of symptoms (CAPE score and acute deterioration score), support from relatives, and support services (meals on wheels and home help). In a separate logistic regression analysis severity of dementia was included with the other key variables (see Table 4.5.2A) but there was absolutely no trace of an association with mortality (Wald = 0.0001,  $p = 0.99$ ) and so it was excluded from further analysis. Table 4.5.2A shows the results of the logistic regression using the log likelihood ratio to remove those variables which were not significantly associated with mortality. Table 4.5.2A shows that the significant associations with higher mortality occur with the variables; anxiety symptoms, CAPE score, meals on wheels and attendance at a day

centre, while the other variables were systematically removed from the model since they did not make a significant contribution to it.

**Table 4.5.2A Factors associated with mortality - logistic regression analysis**

----- Variables not in the Equation -----

Variable	Score	df	Sig	R
Age	.043	1	.836	.0000
Sex	1.159	1	.282	.0000
Admission	.042	1	.837	.0000
Deterioration	1.241	1	.265	.0000
Relatives	.815	1	.367	.0000

----- Model if Term Removed -----

Term	Log Likelihood	-2 Log LR	df	Significance of Log LR
Removed				
Anxiety	-30.28	4.10	1	.0428
CAPE score	-30.53	4.60	1	.0320
Meals on wheels	-3.385	10.31	1	.0013
Day centre	-30.36	4.28	1	.0387

No more variables can be removed

Higher mortality was therefore related to higher CAPE score, presence of anxiety symptoms, provision of meals on wheels and lack of attendance at a day centre. CAPE score is well known to be associated with prognosis. The finding that provision of meals on wheels was associated with a higher mortality may be an indication that the dementia sufferers receiving the service are already quite deteriorated and barely managing with maximum community support. Day centre attendance appears to have a protective effect in some way and this may be a reflection of improved morale and

better care amongst those attending day centres, who may have better access to medical care or fewer physical problems. The link between anxiety and mortality is interesting, not least because it may suggest a possible association with life events. The anxiety may reflect a greater level of distress in some patients who had been taken out of their own environment to be admitted as inpatients and were perhaps having difficulty adjusting to the loss of their familiar surroundings and social contacts. This will be covered in more detail in the discussion section.

A further analysis was performed entering duration of dementia from onset (dated from first symptoms) to follow-up, and including the other variables (including severity of dementia) as above with mortality remaining as the dependent variable. In this analysis mortality was associated with duration of dementia ( $p = 0.0007$ ), female sex ( $p = 0.047$ ), symptoms of anxiety ( $p = 0.0009$ ) and having meals on wheels ( $p = 0.0045$ ).



# DISCUSSION

## ***5.0.0 Scope of the discussion***

The literature review demonstrated how senile dementia has been widely regarded as a purely physical disorder without sufficient regard for possible psychosocial factors which may be influential in its development, course or prognosis. It went on to describe how deterioration in senile dementia cannot be adequately explained by a purely biological concept of dementia, and how studies of relocation and other social change have suggested that social factors may influence its course. The influences of life events on psychiatric and physical disorders are described, and a theoretical mechanism as to how life stress, neuroendocrine function and the dementing process may be related has been discussed.

In this section the results will be discussed, firstly with respect to how they meet the aims of the study, and secondly in the context of the literature and theoretical mechanisms covered in the introduction. The importance of social factors in supporting dementia sufferers and the aggravating factors that potentially precipitate deterioration will be addressed. In addition, the life events results will be interpreted and put into context with previous work. The possible links between mood symptoms, dementia and stressful life change will then be discussed with regard to the course and prognosis of senile dementia.

Suggestions will be made for future research drawing on the findings and difficulties of this study. Lastly, the conclusions of the study will be summarised.

### ***5.1.0 Implications of the pilot study***

Although the results of the pilot study were encouraging, the numbers were too small to draw firm conclusions, and it did not include a control group of dementia sufferers in the community who could be compared with the dementia patients and the fit elderly control group. From the point of view of the logistics of the full study, the pilot study did show that the interviews could be completed within a reasonable time, that they were acceptable to subjects and informants, and that using the particular catchment area population enough dementia patient subjects could be collected within a two to three year time period to allow the study to be finished with adequate numbers of subjects. The completion of the pilot study therefore illustrated that a larger study was not only worthwhile but also feasible within the limited resources and time constraints which the researcher was subject to.

The pilot study was comparable in scale to that of Amster and Krauss (1974), who found double the number of life events prior to senile dementia. However, they used the Geriatric Schedule of Recent Experiences (GRSE), and acknowledged that the decline could have begun prior to the illness being noticed by relatives. In addition, the GRSE did not control for life events which were dependent (i.e. precipitated by the patient's deterioration rather than causing it), and provided no measure of contextual threat or social environment change. The present results showed significantly more life events in the dementia patient group compared to the controls, and suggested that it would be fruitful to expand the study by adding a further control group and by increasing each group to an adequate number of subjects.



### ***5.2.0 Measuring change in routine and environment***

In line with the third aim of this study, new scales were developed which could measure the routine and environment change components of life events reliably. The achievement of reliability between raters required only brief training and suggestions were made as to how the reliability could be further improved.

This meant that the scales should permit reliable testing of the hypothesis, consistent with clinical experience, that alterations in routine and environment may be important factors affecting the clinical state and the process of referral in patients suffering from cognitive impairment. The results in the full study suggest that both scales, and the routine scale in particular, may be useful research tools in studies which seek to measure the social disruptiveness of life events. Further research in this area may facilitate our understanding of how the effects of life events are mediated.

Although these scales are a new development, Brown and Harris (1978) looked at many attributes of life events including *change in routine*, which was rated using a simple four point scale (1 = major, 2 = moderate, 3 = some, 4 = none/minimal). Brown and Harris did not find their change in routine scale useful in judging the overall influence of life events on depression in their study of south London women. This may be because the scale was not operationally defined as it was in this study, and the results may not, therefore, have been reliable between raters. On the other hand, it is possible to argue that subjects with cognitive impairment are more sensitive to the effects of disruptive routine and environment change because they are less well able to use cognitive processes to adapt to new situations. Memory impairment may



also impede their ability to remember what has happened, rendering them less able to process life events emotionally and to come to terms with them, whether the life event was a bereavement due to the death of carer or simply the loss of their home help. For example, if the wife of an elderly man with dementia dies, he may not remember she has died, and may be constantly distressed because he cannot find her, asking everyone who he meets where she is, and even wandering outside at night searching for her. The researcher knows of a case where an elderly woman with dementia lost both her son-in-law and daughter through suicide within two days of each other. For the next year she viewed the tragic event as having happened only three weeks before. This increased its immediacy and its capacity to distress her, giving her no hope for living.

Further research using these scales may be useful in replicating this study in other populations with dementia. It would also be very interesting to see if other groups with cognitive problems (such as mental handicap) are sensitive to such changes occurring in the context of life events. Finally, since these scales are reliable, it would be worth using them in other studies of psychiatric or physical disorder in the elderly, or indeed in younger age groups, to see how they contribute to our understanding of how life events precipitate or exacerbate illness of other types.

### ***5.3.0 Demographic factors and health***

#### **Age and sex**

The high proportion of subjects over 75 reflects the greater incidence of senile dementia with age. The higher proportion of dementia controls in the under 75 age

group may reflect a greater awareness among their relatives of incipient dementia symptoms and a greater motivation to seek help at an earlier stage. However, overall there were no significant age differences between the groups, suggesting that age was not going to be a confounding factor in other analyses. On the other hand, day centres may be more inclined to take on younger and less frail clients, who are likely to live longer and may stand a better chance of managing in the community with appropriate support.

Each of the three groups had a similar sex ratio. The high proportion of females in the study in part reflects the longer lifespan and greater incidence of Alzheimer's disease in females (Amaducci and Lippi, 1992).

### **Education and social class**

The fit elderly control group were of higher educational level and social class than both dementia groups, suggesting that this was a variable which may need to be taken into account in certain analyses. The association of low social class or low educational level with higher rates of cognitive impairment has been found in previous studies (Lindesay et al., 1989; O'Connor et al., 1989; Brayne and Calloway, 1990) and this may relate to the problem of certain questions on brief cognitive tests having a strong educational bias (Anthony et al., 1987b; Orrell, et al., 1992b). Low levels of educational attainment obviously also prejudice against being able to achieve professional or managerial status. There does not appear to be a higher rate of dementia in the working class population (Kay et al., 1964b; Brayne and Calloway, 1990; O'Connor et al., 1991); in particular, the GMSS appears to be free from social



class bias when used as a diagnostic instrument for dementia (Blessed et al., 1991). However, those with a higher educational or social level would generally have to deteriorate further before the symptoms were detectable with standard cognitive tests or caused functional impairment in the community of sufficient degree for input from health or social services to be necessary. This might explain the over-representation of low educational and low social class subjects in the two dementia groups.

### **Mental health**

Not unexpectedly, considering the genetic contribution to Alzheimer's disease, there was a significantly higher rate of dementia in first degree relatives of sufferers. This may be an underestimate because many informants were younger than the dementia sufferers, and therefore may not have been aware of possible dementia in other family members. It is interesting to note that the dementia patient group had a higher rate of previous psychiatric admissions for psychiatric problems other than dementia. This may be due to misdiagnosis during previous admissions when behavioural problems or mood change compatible with early dementia may be mistaken for another illness, or to a previous history of depression predisposing to the development of dementia as has been suggested in reviews of other studies (Amaducci and Lippi, 1992).

### **Physical health**

The selection procedure omitted people with dementia who had serious physical problems that might affect their cognitive function. This was done because physical illness is a common factor precipitating admission in people with dementia (Patterson & LeClair, 1989) and physical illness had to be controlled for in order to include only



dementia sufferers who were admitted because of a mental deterioration. Although the dementia patient group had a higher rate of previous cardiovascular problems than the dementia control group, this was not reflected in higher levels of senile dementia involving a vascular component. In fact, the total levels of vascular dementia (multi-infarct plus mixed) were the same in both groups, comprising about 20% of all dementia cases. The higher rate of current mild cardiovascular problems in the dementia patient group is probably not important from the point of view of factors leading to admission. This is because the rating 'mild' covered either risk factors (e.g. hypertension, atrial fibrillation) for the development of more serious illness or well-controlled chronic problems (such as mild congestive cardiac failure) which by definition would not have been deteriorating prior to admission. Deteriorating serious physical health problems would have been under the 'moderate' or 'severe' categories.

The overall rate of current cardiovascular problems in the admitted dementia patients (30%) is similar to the 32% found in a study of dementia day hospital patients (Bergmann et al., 1978), but lower than the 49% found in Part III local authority residential homes (Gosney et al., 1990). In addition, the rate of respiratory problems (14.3%) was almost exactly the same as Bergmann's (15%), but higher than the rate of only 10% in the Part III homes study. In this study the rate of metabolic endocrine disorders was slightly higher (14.3%) compared to the 10% in Bergmann's and 13% in the Part III homes (Gosney et al., 1990).

It is likely that some of the patients with the more severe physical problems who were thereby excluded from the present study were admitted as inpatients. This would

explain the close similarity between the rates of some of the more common physical disorders in this study and that of Bergmann et al. (1978). It is also important to point out that dementia patients who have severe physical problems are more likely to be admitted to geriatric wards, and so would not be included in the total sample for this study even though they were in the same catchment area.

However, it is interesting to note that the two dementia groups had rates of orthopaedic problems (20% and 22%) about half of the rate of the 40% in the fit elderly community controls. Gosney's study found 23% of part III residents had orthopaedic problems.

Comparing the various categories of physical illnesses in Gosney's study with this study, it appears that Gosney's Part III residents had higher levels of physical disorders than all three of the groups in the present study. There was an average of almost exactly one physical condition per subject in each of the groups in the current study. When the three groups in this study were compared for overall levels of physical health problems, there were no differences in past or current physical ill health.

In summary, the dementia patients in this study appeared to be no more physically ill than the two control groups, and were generally fitter than the average Part III resident. This suggests two things: first, that the exclusion procedure was effective in removing patients with the more severe physical disorders that might affect their mental state; and second, that the dementia patients were not primarily admitted because of physical problems.



### **Physical disability and sensory impairment**

The physical disability and sensory impairment results have largely been discussed in the results section, where it was concluded that the dementia patient group were no more physically disabled than the control group of mentally-fit elderly. Indeed, the vast majority (72-83%) of subjects in all three groups were mobile and had not recently deteriorated in mobility. Equally, there was no difference in the rates of sensory impairment (vision and hearing) between the two dementia groups. This suggests that neither sensory impairment nor deterioration in mobility was a key factor contributing to admission in the dementia patients.

### **Accommodation**

As has been noted in the results, the fit controls were less likely to live in council accommodation than subjects in the two dementia groups, perhaps because the former had a larger proportion of high social class subjects. The general condition of the subjects' accommodation was uniform across the groups. Since both council and private accommodation were in reasonable condition, accommodation *per se* did not contribute to admission in the vast majority of the cases.

### **Support services**

As would be expected because of the needs of sufferers, the two dementia groups had a higher use of various statutory services such as home help, meals on wheels, social work, district nurses and community psychiatric nurses. The dementia controls used day centres more often (because they were drawn from people either attending them already or on the waiting lists of the two day centres involved).



### ***5.3.1 Social factors and deterioration***

#### **Social situation**

The dementia controls had a higher degree of support from relatives than the dementia patients, who in turn had more support than the fit elderly. In addition, few dementia control subjects lived alone compared to the other two groups. There may be a number of reasons for this finding. Dementia sufferers with support from relatives are more likely to be sustained in the community compared to those who live alone (Bergmann et al., 1978). Dementia sufferers with support may also be more likely to be referred to and accepted by day centres, who may see them as more likely to engage and attend regularly, with the prospect of being able to maintain them in the community, whilst supporting the carer.

Although 70% of dementia controls had regular daily support from relatives, only about half actually lived alone. This can be accounted for because many relatives lived nearby and visited one or more times daily. In terms of regular social contacts, the data on the dementia controls are not really comparable with the other two groups, because attending a day centre contributed greatly to the number of social contacts per day. However, considering that nearly 75% of the dementia patients had four or more social contacts per day and significantly more social contacts than the fit elderly, isolation does not seem to be an important contributory factor to the admission process.

Social support is important for the elderly (Lam and Power, 1991). It is obviously more difficult in a population with dementia to enquire about the quality of social

support (Henderson et al., 1986a), but a study from Australia suggested that the elderly living alone are not more likely to be suffering from dementia (Henderson et al., 1986b). The picture from the current study suggests that in the process of developing dementia, the individual does not lose overall social support, and indeed may gain some through closer involvement of relatives as the illness starts to impair functioning and the sufferer needs extra help.

### **Quality of relationship with carer**

Despite the importance of carers in the management of dementia, this discussion will not cover the abundance of literature relating to carer stress and carer psychological problems: this study focuses on the individual with dementia rather than on the carers themselves. However, there have been a number of studies relating to the relationship between carers and sufferers, and the literature on this will be addressed in conjunction with the results of this study.

The scales used in this study to assess the quality of relationships with carers were developed using 60 elderly psychiatric inpatients or day patients and their carers (Bergmann et al., 1984). Bergmann's group found that a poorer outcome at three months was associated with a lower level of positive communication in the relationship between patient and carer. The present study found that the dementia patients had a significantly lower level of positive communication with their carers than did the dementia controls, again suggesting that a better quality of relationship may be associated with a better outcome and a lower likelihood of admission. However, in this



study the association might be spurious, since deterioration may lead to a poorer quality of relationship, rather than vice versa.

Bergmann et al. (1984) also found that a poor outcome in their dementia group was associated with a higher level of physical dependency and a lower level of autonomy. This would fit with the findings in the present study that carers of dementia patients felt less autonomy in their relationship with them than did carers of the dementia controls, even though the dementia controls were slightly more physically dependent. Indeed, some studies have shown that more dependent dementia sufferers may be more manageable, and that it is behavioural disturbance which causes more stress on the carer (Isaacs et al., 1972; Gilleard et al., 1982). There are many mediating factors which need to be taken into account (Morris and Morris, 1993), and further work is needed in this area before the causal direction can be properly assessed.

Other studies looking at the interaction between relatives and psychiatric patients have assessed 'Expressed Emotion' (Vaughn and Leff, 1976). Several studies have now used this method to examine the relationship between carers and dementia sufferers (Orford et al., 1987; Gilhooly and Whittick., 1989; Bledin et al., 1990). Gilhooly and Whittick found that female carers and those with lower morale had a higher level of critical comments in the relationship. In addition, a better quality of past relationship was associated with fewer critical comments. The level of help and services received was unrelated to Expressed Emotion (EE), however in Bledin's study, which looked at carers who were daughters, high EE was associated with a higher level of strain and distress, whereas fewer critical comments and more positive remarks (low EE) was



associated with better coping strategies. On the other hand, EE level was not related to whether or not the dementia sufferer remained supported in the community at nine month follow-up. However, the number of subjects was small (only 25) and the follow-up period was relatively short.

Overall, the studies (including this one) appear to indicate that negative communication in the relationship between the dementia sufferer and carer makes the caring process more difficult. This is because it can lower carers' morale, increase the feeling of stress and burden, and possibly lead to a poorer patient outcome in terms of worsening problems or an increased likelihood of psychiatric admission.

In order to see whether one dementia group had significantly more support than the other, the two groups were also compared for overall levels of support using multivariate analysis. District nursing input was more common in the dementia controls, whereas more dementia patients received social work help. Social work input is more likely to reflect times of increased need, acute deterioration and the patient being at risk. District nursing input is more likely to reflect physical dependency (e.g. the need for help with bathing), and to be a stable, continuing resource helping the dementia sufferer to be maintained in the community. Although the dementia controls had more support from relatives, they were also less likely to have negative communication with them than the dementia patients with their relatives. Negative communication may make relatives feel less able to cope with behaviour problems and deterioration, or alternatively may reflect the deteriorating mental condition of the

dementia sufferer in the period preceding admission. Thus, negative communication may be a factor which can increase the risk of admission and influence prognosis.

### ***5.3.2 Psychiatric symptoms, dependency and acute deterioration***

#### **Diagnosis**

The proportions of the various senile dementias in the two senile dementia groups are broadly in line with the expected proportion of such degenerative dementias in the community, with around three-quarters comprising Alzheimer's disease, one fifth vascular dementia (including mixed Alzheimer's disease and vascular dementia) and a few per cent of other types (Lishman, 1987). The analyses comparing the dementia groups were not stratified by diagnosis for three reasons. Firstly, reliable distinction between vascular dementia and Alzheimer's disease is arguably not possible in field studies (Henderson and Jorm, 1987; Lindesay et al., 1989). Secondly, there is currently no evidence to suggest that social factors differentially affect these two types of dementia. Lastly, the dementia sub-groups would probably have been too small for meaningful comparison.

#### **Severity of dementia**

It is interesting to note that there was no overall difference in the severity of cognitive impairment between the two dementia groups, as this is an important measure of the overall severity of dementia. This suggests that dementia patients were not admitted because they had a more severe dementia than the controls.



### **Depressive and anxiety symptoms**

Depressive symptoms are very common in senile dementia; even so, quoted rates vary widely in Alzheimer's disease (AD) from 0% (Knesevich et al., 1983) up to 87% (Merriam et al., 1988). However, the overall rate is probably between 15% and 30% (Cummings et al., 1987; Burns et al., 1990). In vascular dementia, some studies suggest that the rate of depressive symptoms is higher than in AD, perhaps up to 60% (Cummings et al., 1987). In the current study, 19% of dementia patients and 26% of dementia controls had depressive symptoms using the GMSS, which is very close to the rate of 23.3% found by Burns using the GMSS on a population from the same catchment area. Symptoms of anxiety are common in senile dementia (Dodwell, 1987; Kaplan and Sadock, 1988), and may manifest at an early stage if the individual is aware of their gradual progressive memory and intellectual deficits. In addition, anxiety commonly occurs as part of a depressive syndrome in dementia.

### **Other psychiatric symptoms**

Other studies have found a variety of rates of delusions in Alzheimer's disease (AD), from 15.7% (Burns et al., 1990) to 30% (Cummings et al., 1987), while the reported rate of hallucinations varies even more from 3% (Cummings et al., 1987) to 16.9% (Burns et al., 1990) and even as high as 49% (Rabins et al., 1982). In the present study there was a relatively low rate of patients with schizophrenic/paranoid symptoms (3-8%) according to the GMSS results. This is primarily because other studies used informant interview and historical data, whereas this study relied on patient interviews, which are likely to elicit fewer such psychotic symptoms since patients with dementia may forget their past delusions/hallucinations and only experience them at certain



times, in certain situations, or when physically ill. In addition, the coding method of the GMSS tends to pick up symptoms which are clearly abnormal, rather than vague or transient ones: this will also tend to reduce the rate. Studies which specifically set out to collect psychiatric symptoms may attempt to identify symptoms which have occurred since the beginning of the illness (even if this was several years ago), which will also increase the rate of symptoms detected. For example, Burns et al. (1990) found 15.7% of AD patients had delusions at some time during their illness, whereas only 10.7% had experienced them in the past year. It follows that a study such as the present one which looks only at current delusions reported by the patient will give lower estimates. On the other hand, in the current study the CAPE ratings indicated that 23% of dementia patients and 40% of dementiacontrols had some paranoid ideas (including delusions) according to the informants; these figures are more in line with the earlier studies. In summary, the differences in the level of schizophrenic/paranoid phenomena recorded in this study compared to other studies can be accounted for by the different definitions and methods of data collection, and by the fact that other studies looked at the phenomena over an extended period whereas this one used GMSS criteria at interview.

### **Behavioural symptoms and dependency**

There were no overall differences between the two dementia groups in the levels of behavioural disturbance and dependency as measured by the Behaviour Rating Scale (BRS) of the CAPE. Each group had a mean score of 14 out of 36. Perhaps surprisingly, the mean of 14 on the BRS was exactly the same as that stated in the CAPE manual (Pattie and Gilleard, 1979) for acute psychogeriatric patients (as the

dementia patient group was). Overall, both dementia groups were more dependent than the group of psychogeriatric day care attenders studied by Bell and Gilleard (1986). However, their levels of physical dependency (means 5.5 and 5.6) were about the same as the psychogeriatric day hospital group seen in Bell and Gilleard's study, and this is again close to the mean of 5 (in the CAPE manual) for the physical dependency level of acute psychogeriatric patients. About a quarter of each dementia group was classified as 'maximum dependency' by the BRS, which according to the manual suggests that this group was as dependent as patients on continuing care psychogeriatric and geriatric wards (Pattie and Gilleard, 1979). Incontinence and disturbed behaviour at night were more common in the dementia patient group, and both these may be particularly problematic for the carer (Gilleard, 1984; O'Connor et al., 1990), and likely to be associated with an admission to hospital rather than a residential home (Lam et al., 1989).

These results suggest that there is no overall differences in the level of behavioural disturbance and dependency between the two dementia groups in this study, although certain problem behaviours appear to be more common in the patient group. In addition, the BRS scores are comparable with those reported in other studies, suggesting that acute psychogeriatric patients from different catchment areas may have similar mean levels of dependency.

### **Acute deterioration**

This new score, developed for the current study, was intended to use information from the informant in order to rate how much a dementia patient had deteriorated in the



period preceding the date of admission (or interview, in the controls). It provided a measure of overall deterioration. The reliability study in section 4.4.0 shows that the individual items of the acute deterioration score are reliable between raters, and also that there is a very high correlation between the overall scores for the two raters. The overall score predicted decision to admit in a group of elderly psychiatric patients (other than those used in the main life events in senile dementia study). These results suggest that the score is a reliable and valid measure of deterioration, appropriate for use in relation to life events. The dementia patients had significantly higher deterioration scores (than the dementia controls) indicating that they had deteriorated more over recent months. This is the first study in which the score has been used, and replication of the method by an independent group would clarify its potential usefulness in further studies.

When the dementia groups were compared using multivariate analysis, presence of a cohabitee made no difference to the total CAPE and acute deterioration scores. However, cohabitee carers of dementia patients were more likely to report disturbed behaviour at night than were cohabitee carers of dementia controls. This is understandable, since disturbed behaviour at night is very stressful and tiring for carers, making it more difficult for them to cope. It also reflects one aspect of deterioration in dementia sufferers.

The individual acute deterioration ratings cover many problems which are known to be associated with admission and difficulties for the carer. These include: sleep disturbance, incontinence, wandering, agitation, and disturbed and aggressive



behaviour, depression and withdrawal (Sanford, 1975; Rabins and Nicholson, 1991; Morris and Morris, 1993). The carer's ability to cope relates to the dementia sufferer's symptoms. This again suggests that the acute deterioration score may be valuable in assessing deterioration and as a predictor of admission.

As part of a clinical evaluation, the acute deterioration score might help to predict an admission. This has service implications: where admission can be predicted, perhaps preventative measures can be taken to avoid it; or a planned respite admission might avoid an acute crisis admission where the support network has broken down. Such crisis admissions are often complicated by additional risks to the health of the patient and the well-being and resilience of the primary carer who may feel that s/he can no longer cope in future whatever support is provided. Because of this, the end result of a crisis admission may well be the sufferer going into institutional care. This is usually more expensive than care in the community, but more importantly, carers (and patients) often prefer the patient to stay at home where they often have a better quality of life (if appropriate support is available) and more independence.

### ***5.3.3 Life events, admission and deterioration***

This section of the results addressed the first aim of the study, which was to investigate the hypothesis that *'recent life events are related both to acute deterioration of senile dementia and to the patients presentation to services'*. As shown in Figure 4.3.3, life events (of all levels of threat) appeared to be more common in the fortnight before admission in the dementia patient group than in the two control groups. However, there is also a peak for the fit elderly controls at four weeks before

interview date. For this finding there is no obvious explanation. If one accepts that the peak in the controls is due to recall effects such as telescoping of events or distal forgetting, it follows that this explanation ought to apply to the dementia patient group too. However, the LEDS has been shown to be valid and reliable in elderly samples even when used by previously inexperienced raters after only brief training (Wilkinson et al., 1986). Equally, identifying a threatening life event is not dependent on the age of the panel (Orrell and Davies, 1994), although age of the rater may affect the level of threat seen in the event (Davies, 1993).

In Figure 4.3.4, the dementia patients also have an excess of life events in the two weeks preceding acute deterioration compared to the two control groups. This suggests that life events tend to precede deterioration, but they may not necessarily have a causal role.

Since life events in the dementia patients showed an excess both in the two weeks before admission and the two weeks before deterioration, this suggests that the result is consistent and that life events are more frequent before both deterioration and admission in dementia patients. The result for the fit elderly controls may be coincidence, but firm conclusions should not be drawn solely on the basis of these findings.

### **Life events preceding admission**

While there is no overall difference between the three groups in the total number of life events experienced in the six months before admission, and while the mean



number of life events per subject is also similar, the picture changes when analyses are restricted to severe (marked or moderate threat) life events. A general excess of life events in the dementia patient group and the fit elderly controls (to a lesser extent) emerges compared to in the dementia controls. This suggests that dementia sufferers who are stable in the community have a lower rate of threatening life events than those who are in the process of acutely deteriorating. Moreover, it suggests that they also have a lower rate of severe life events compared to the fit elderly in the community, although the differences were not significant. No other studies have been carried out looking at a stable community population with dementia, so we do not have a clear idea about what the actual life event rate is, but arguably such people are likely to have a lower rate of life events than the fit elderly because they have less involvement in social and other activities. This is as a result of their declining cognitive function limiting their general abilities.

Comparing the three groups over the whole six month period before admission, only the dementia patients had a greater proportion of subjects with life events. The excess of life events in the fit elderly applied only to the first three months; also, life events tended to be restricted to the same individuals rather than the entire group. This may reflect recall effects, or it may reflect higher levels of activity and interaction in some of the fit elderly people, which gives rise to more opportunities for life events.

When only life events which are independent are included, the difference between the three groups lessens, indicating that some of the excess might be accounted for by life events which the dementia patients may themselves have precipitated in the course of



the deterioration leading to admission. The same pattern was seen when independent and possibly independent events were included in the analysis, i.e., there were still no significant differences between the results. If there is a real difference between these groups, it is unlikely to be a very large, and would therefore require larger samples to achieve significance.

One implication of these results is that dementia sufferers may have intrinsically different life event rates from fit elderly, which emphasises the need for the two control groups in this study. There is also a possibility that despite previous work suggesting that informants were able to give a full account of severe life events in this group of patients, the use of an informant may have led to a loss of information.

The overall rate of life events in the fit elderly varies in other studies according to the locality under survey. In populations of high social class such as the elderly in Oxfordshire (House et al., 1990), and Perth, Australia (Emmerson et al., 1989) there is a comparatively low rate of severe life events (13-19% of control subjects over the course of a year), whereas in poor working class areas of London (Murphy, 1982; Evans and Katona, 1993) there may be a higher rate: 19-31% in the preceding year.

In the current study there was an even higher rate of severe life events (42%) in the fit elderly control group, for which there is no obvious explanation. The present study included Peckham, which is a deprived area and so would tend to increase the number of severe life events. In addition, the mean age of the fit elderly subjects was 81 in this study compared to 70 in the Oxford study and 74 in Islington (Evans and Katona,

1993). The Perth study did not give a mean age, but judging from the distribution of the age groups and the fact that less than 20% were 80 or over, the estimated mean age would be around 71-73 years. Murphy's study also did not give a mean age but subjects were matched for sex and age group with depressed patients, of whom 56% were aged 65-74 and 44% were aged 75-87. This suggests that the mean age would probably be under 75.

The reason for the greater age of the current sample is simply that the other studies were investigating depression (except for the Oxford study, which looked at stroke) which is relatively common at all ages over sixty-five. In contrast, senile dementia, which is far less common at 65 (1% of population) but much more common as age increases (with around 20% of the over 80s affected). Since the fit control group were age and sex matched with the first 50 dementia patients, their average age was bound to be considerably older than the control groups in the other studies. Thus, in the present study, the older sample and the deprived location might together provide an explanation for the higher rate of life events in the fit elderly.

Although life events tend to decrease with increasing age (Orrell and Davies, 1994), the rate in the very elderly population is not known. When the data was reanalysed to examine whether life events increased with age in this elderly sample, there was a trend for those experiencing severe life events in the preceding six months to be older ( $p = 0.071$ ). When only independent severe life events were included the trend disappeared ( $p = 0.220$ ). However, since the purpose of the analysis was to see whether life events increased with age in the fit elderly control group, the three groups



were analysed individually. When this was done, neither dementia group showed any association between life events and age, but the fit elderly controls who had experienced severe life events were significantly older than those with no events ( $t = -2.52$ ,  $p = 0.015$ ). Moreover, for these fit elderly controls, this relationship remained when only independent severe life events were included ( $t = -2.24$ ,  $p = 0.030$ ). Subjects who had experienced life events had a mean age of 83, four years older than the mean age of those who had not experienced life events. These results support the hypothesis that the excess of life events in the fit elderly controls was related to their advanced age.

In the original protocol, power analyses suggested that if the dementia patients had a life event rate of 40% and the controls had a life event rate of 20% there would be a 95% chance of demonstrating a significant difference at the  $p < 0.01$  level. If this study had a rate of severe life events similar to that of the fit elderly controls in previous investigations (between 13-31%), the life event rate in the dementia patients (54%) would have been significantly different from the fit elderly controls. The actual rate of life events in the fit elderly controls was unexpectedly high and appears to be related to their advanced age.

### **Life events and acute deterioration**

When the period four weeks before acute deterioration was compared with an equivalent period in the two control groups (to allow for supposed recall effects) there were more severe life events in the dementia patients than in both the dementia controls and the fit controls. However, the reduction in the number of dementia



patients with a severe life event when only independent (and possibly independent) events are included suggests that the significant excess of stressful life events in this group could be accounted for by life events resulting from the deterioration rather than provoking it. However, there still remains a (non-significant) excess of life events in the dementia patient group, and it is therefore possible to consider a role for life events in precipitating deterioration in some dementia sufferers.

The first hypothesis stated in the aims suggested that *'life events are related both to acute deterioration of senile dementia sufferers and the patient's presentation to services in dementia sufferers'*. The results did not find this hypothesis to be true although the existence of trends make it possible that larger samples would show significant associations in senile dementia sufferers both between life events and admission, and between life events and deterioration. The study therefore needs to be replicated using larger samples, in particular because the unexpectedly high rate of life events in the fit elderly control group in this study might be a statistical outlier.

### **Social class**

The analysis of social class in relation to life events allowed two questions to be examined. First, was social class related to the number of life events in each group? In particular, were working class subjects more likely to have severe life events? Secondly, were there significant differences between the three subject groups when social class was controlled for (by stratifying the three groups)?

In other studies, low social class (4 or 5) was associated with a higher rate of severe life events (Murphy, 1982; Brown and Harris, 1978). However, in this study low social class was only linked with more frequent life events in the dementia control group, and when independent events only were included the difference was no longer significant. In the dementia control group, the difference was the result of an excess of dependent events. Moreover, social class differences between the dementia groups cannot account for the excess of life events in the dementia patients. The reason for this are: firstly, because there is no excess of low social class subjects in the dementia patients; and secondly, because the association between low social class and events only occurred in the dementia control group. Although social class did not appear to be important across the groups, the results indicated that it should be included in later multivariate analyses.

### **Type of admission**

When the types of admission of the dementia patients were compared according to whether or not they had an inpatient or day patient psychiatric admission, there was found to be no difference in stressful life events between these two groups. The type of admission also made no difference when each of these groups was compared with each of the two control groups. Thus, in dementia patients, type of admission seems to be unrelated to life events. This was an important finding since it corroborated the absence of a significant relationship between life events and admission in dementia sufferers found in the earlier analyses.



### **Severity of dementia and life events**

Since it is not unreasonable to argue that subjects with milder dementia (according to the GMSS level of cognitive impairment) are more able to appreciate (and are therefore more sensitive to) threatening life events than subjects with more severe dementia, life events were examined in relation to severity of dementia. There were no significant associations between group, severity of dementia and the occurrence of life events. However, patients with mild dementia experienced many more life events in the three months preceding admission than controls with mild dementia (and all other sub-groups). Thus, in subjects with mild dementia, there may be a trend for life events to contribute to the deterioration leading to an admission or to increase the risk of admission *per se*. However, the numbers in the sub-groups were quite small.

When confounding variables such as educational level, social class and age were controlled for in the multivariate logistic regression analysis, the occurrence of life events remained unrelated to the severity of the dementia. Considering that life events were linked to the informant's assessment of cognitive impairment by the BRS and acute deterioration score items, it is interesting to note that no relationship was found between life events and cognitive impairment with the GMSS interview. The GMSS also was more concerned with assessing the current state of cognitive function at interview rather than decline over time. Equally, relatives may be more sensitive to signs of further cognitive deterioration. A further possibility is that since relatives could have been biased by effort after meaning since they had to give information on life events, BRS and deterioration. In addition, after psychiatric admission the patient may decompensate as a result of the disruption to their life and coping systems that



admission entails. This decompensation may serve to obscure a potential decline in cognitive function in response to life events.

### **Life events and mood symptoms**

Several studies in the elderly have found that severe life events can precipitate depressive illness (Linn et al., 1980; Murphy, 1982; Patrick and Moore, 1986; Lam et al., 1987; Emmerson et al., 1989; Evans and Katona, 1993). The propensity for life events to cause depression has not been studied in people suffering from dementia, although there is no reason to think that they would be immune from the effects of such stress; indeed (as has been argued in the introduction) there is good reason to think that, if anything, dementia sufferers may be more sensitive to the stress and change produced by life events. On the other hand, it could also be argued that in severe dementia there might be insufficient cognitive power to comprehend and appreciate the threat element of life events. For this reason, depressive symptoms were examined with respect to life events. In addition, because a large proportion of the dementia sufferers had anxiety symptoms, and because conceptually it is a small step from the precipitation of depression to the precipitation of anxiety, anxiety and life events were also examined for a possible relationship. The results showed that independent severe life events occurring in the preceding four to six months were associated with depressive symptoms in both the dementia patients and dementia controls. There were no such associations in the fit elderly control group, but since subjects with depressive symptoms were removed as part of the screening procedure, there was a very low frequency of depressive symptoms in this group.

Once again, logistic regression analysis was used on all dementia subjects to control for possible confounding variables (group, social class, severity of dementia, and conflict in the relationship between carer and sufferer). The most significant predictor of depressive symptoms was independent severe life events in the preceding four to six months, although increasing age also contributed to the model.

There is no clear relationship between the severity of Alzheimer's disease and the presence of depressive symptoms (Alexopoulos and Abrams, 1991). Although some studies have found increasing age to be associated with severity of depressive symptoms, others have not (Katona, 1991). The relationship between age, depressive symptoms and senile dementia does not appear to have been addressed in recent reviews. The results in this study have indicated that life events may have a key role in precipitating depression in senile dementia sufferers. This is important since it shows that people with senile dementia are sensitive to distressing experiences, and react in a similar way to the cognitively intact population. It also has implications for the care of dementia sufferers.

One possible mechanism for this relationship is that life events precipitate cognitive decline which in turn leads to depressive symptoms. However, there was no difference in levels of cognitive impairment and depressive symptoms between the two dementia groups, and the logistic regression analysis removed severity of cognitive impairment very early on in the stepwise elimination procedure. This mechanism also appears unlikely, because of the well-established finding that threatening life events lead to depressive symptoms (rather than cognitive decline). This work needs to be replicated.



However, the results of this particular analysis which links life events with depressive symptoms are highly significant, the possibility of this having occurred purely by chance being less than 1 in 5000.

However, as has been discussed in the introduction, there is now sufficient theoretical and experimental evidence to suggest that the interactions of stress, ageing and the neuroendocrine system might play a role in the loss of hippocampal neurons which occurs in the process of dementia (O'Dwyer and Orrell, 1994). The results of the present study should not be seen as ruling out the possibility that life events and cognitive decline might be associated, and ways of investigating this will be discussed in the future research section.

Symptoms of anxiety were also significantly associated with life events in the four to six months preceding admission, but only in the dementia patient group. One explanation for this is that life events cause a propensity to anxiety which is then augmented by the additional disruptive experience of being admitted to hospital. The stress of the life event may overload the individual's residual coping capacities, leading to anxiety. In the dementia controls, life events were not followed by the additional stress of the admission process, and this may explain why events in this group were not associated with anxiety. However, there was no difference in the overall rate of anxiety in the two dementia groups. In a logistic regression analysis, depressive symptoms (but not life events) were significantly associated with the presence of anxiety symptoms. This suggests that the link between anxiety and life events is



indirect, and merely reflects the much stronger associations between depressive symptoms and anxiety symptoms, and between depressive symptoms and life events.

Since the depressive symptoms were not dated, the symptom onset might have been much closer in time to the life event than was suggested by the interview date. It is therefore possible that events may have precipitated depression fairly quickly. These results at least suggest that life events can cause distress and negative mood in individuals with dementia. However, without exact dating of the mood symptoms (by informant presumably) it is not possible to say how often depressive symptoms occurred after and because of life events. There is no good theoretical case for suggesting that life events lead to admission by way of precipitating negative mood because the overall rate of depressive symptoms was similar in both control groups. In addition, it has been shown that life events were associated with depressive symptoms *independently* of dementia group.

### **Life events and level of dependency**

The sufferer's level of dependency is very important in terms of level of support needed and carer stress. For this reason it was relevant to examine a possible link between increased dependency and stressful life events. The CAPE BRS scores measured the present level of dependency rather than a recent deterioration. There were no significant differences in the mean BRS scores between the two dementia groups. There was also no difference in mean BRS scores in those with or without severe life events for either dementia group. When individual items of the CAPE BRS score were looked at, only the degree of cognitive impairment (as rated by the

informant) in the dementia patients was significantly associated with severe independent life events. Studies have indicated that accurate assessment of cognitive decline is possible by informant interview (Jorm and Jacomb, 1989). This suggests that either cognitive impairment may be worsened by life events, or that cognitive impairment increases the risk of life events. It is also possible that relatives who are aware of life events are more likely to rate a higher severity of cognitive impairment, or that relatives who note increasing cognitive impairment may be more likely to recall life events.

These results suggest that the threatening life events do not appear to significantly undermine coping mechanisms, leading to increased dependency, for either of the dementia groups. Although the finding of an association between informants' rating of cognitive impairment and life events is interesting, its relevance is uncertain.

### **Life events and the acute deterioration score**

In earlier analyses, it was possible to investigate life events in subjects who had a datable deterioration; however, this did not address the potential relationship between the severity of deterioration and the occurrence of stressful life events. As senile dementia is an illness which deteriorates over time in any case, the acute deterioration score was used as a measure of the severity of this deterioration in the preceding year. The relationship between stressful life events and the total acute deterioration score was looked at in several ways. First, the relationship between total deterioration score and occurrence of life events preceding admission was examined in each dementia group. Secondly, the dementia groups were merged and deterioration score was



compared for those sufferers with and without life events. Thirdly, the relationship between deterioration score and life events preceding deterioration was examined in the sub-group of the dementia patients with datable deterioration and in the dementia controls (who by definition had not had significant recent acute deterioration, as this would have excluded them from the study). Lastly, the individual items of the acute deterioration score were looked at with respect to life events.

The results did not suggest an obvious link between life events and the deterioration score in the period before admission, although interestingly there was a tendency ( $p = 0.09$ ) for dementia controls who had experienced a life event to be rated higher on deterioration compared to their counterparts without life events in this time period. When the two dementia groups were merged, sufferers who had experienced severe and independent severe life events had significantly higher mean deterioration scores. This relationship was more evident in the dementia control group, which suggests that life events may act as a catalyst, increasing the rate of deterioration in some individuals with senile dementia who would have otherwise been fairly stable.

Life events were then related to specific items from the acute deterioration score in each of the dementia groups to see if they appeared to provoke deterioration in certain symptoms or behaviours. There were no significant associations in the dementia control group. However, in the dementia patient group, deterioration in sleep disturbance, wandering/restlessness, and cognitive function were all significantly related to the occurrence of severe (and independent severe) life events. More distant life events (four to six months before admission) were linked only with increased sleep



disturbance whereas recent life events (zero to three months before admission) were associated with sleep disturbance, cognitive deterioration and increased wandering/restlessness. Thus it is possible that life events have a more prolonged effect on sleep disturbance than on the other symptoms.

The finding that life events are significantly linked with informants' accounts of cognitive deterioration strengthens the likelihood that the result represents true association, since the BRS cognitive impairment item was also found to have a significant association with life events.

Earlier analyses have shown that stressful life events are linked with depressive symptoms. It is possible that some of the items of the acute deterioration score which appear to be linked with life events might actually reflect depressive symptoms in the sufferer rather than a new association. For example, sleep disturbance, cognitive impairment and agitation (similar to wandering/restlessness item) are all commonly associated with depressed mood in the elderly. This suggests that these results may actually reflect the highly significant association between depression and life events rather than a new finding.

In summary, stressful life events appear to be related to the overall level of deterioration (as measured by the acute deterioration score). The association between life events and deterioration in certain symptoms may in part reflect the link between life events and depressive mood.

### **Life events, psychiatric symptoms, deterioration and dependency**

In order to control adequately for other variables, logistic regression analysis was used to identify factors predicting membership of one or other dementia group. In addition, the analysis was repeated on all dementia subjects to examine factors predicting the experience of severe life events. When the other factors (psychiatric symptoms, CAPE score, deterioration) were taken into account, severe life events were still not significantly associated with membership of the dementia patient group.

Severe life events appear potentially to precipitate acute deterioration, depression, behavioural changes, and worsening of cognitive function (according to informant ratings). Although previous studies have not examined life events in this way, Amster and Krauss (1974) used a checklist method to study life events in the preceding five years for elderly females with dementia compared to a fit elderly female control group. The individuals with dementia had both more life events and a greater severity of life stress overall compared to the fit elderly. Because they did not assess independence of events it is uncertain whether the events were the cause or merely the result of the dementing process. However, in the face of this interesting finding, it is surprising that so little work has been done to develop this line of investigation over the last twenty years.

One form of life event that has been studied is relocation. The evidence suggests that elderly dementia sufferers are amongst those most severely affected by relocation, with resulting cognitive deterioration and depression (Anthony et al., 1987a). Moreover,



those with the more severe dementia and higher levels of dependency do worse (Pattie and Gilleard, 1978; Crank and Zweig, 1980; Anthony et al., 1987a).

The current study has several advantages, being uniquely able to look at life events, symptoms and dependency. In particular, it uses some of the best available instruments for this sort of research. It uses the LEDS, which is probably the best method for eliciting and rating life events. The study also uses the GMSS, one of the best established and most validated psychiatric diagnostic instruments for the elderly, which provides ratings of the severity of various symptoms. Lastly it employs a measure of behavioural dependency (BRS) and a new measure of the severity of deterioration.

As has been reviewed, the relocation research tends to support the evidence from this study that life events can lead to deterioration in symptoms and functioning. However, only the threat dimension of life events has been discussed so far. The next section will address how life events with social environment change affect senile dementia.

#### ***5.3.4 Life events, routine and environment, and deterioration***

As has been discussed in the introduction, research has suggested that routine and environment change may be particularly disruptive for dementia sufferers. This part of the study sought to measure these aspects of life events and then assess whether life events with routine and environment change were associated with deterioration and admission. In doing so it addressed the second aim of the study: *'to investigate the hypothesis that deterioration in senile dementia is related to certain characteristics of*



*life events, in particular to associated change in the patient's social routine and perceptual environment', and the third aim: 'to develop new scales to measure the changes in social routine and perceptual environment occasioned by life events'. The two new measures of routine and environment change were shown to be reliable (Orrell et al., 1990). Changes in routine were significantly associated with changes in environment, which is understandable since any form of move or relocation tends to involve some change in social support. As shown in Figures 4.3.8A and 4.3.8B, routine change events and to a lesser extent environment change events were more common in the dementia patients in the weeks preceding admission compared to the two control groups. Overall, severe threat life events were far more common than those with either routine or environment change. There was no significant association between either severity of routine change and severity of threat, or severity of environment change and severity of threat. This suggests that these measures are not directly related.*

### **Routine change**

Routine change was significantly more common in the dementia patients than in the two control groups. When the number of subjects experiencing routine change life events was examined, there was again a significant excess of life events in the six months before admission for the dementia patients, and this continued to be the case when only independent life events were included. This clear pattern also remained when only severe threat life events were included. Life events involving routine change were also significantly related to succeeding deterioration. Routine change life events also greatly increased the relative risk of admission for dementia sufferers.

These results indicate that (regardless of the severity of threat) independent life events which disrupt a dementia sufferer's routine may precipitate or worsen deterioration leading to admission.

### **Environment change**

Overall, far fewer subjects in all three groups had life events which involved change in environment. This obviously increases the chances of a type II statistical error i.e. finding no difference when a true difference exists between the two groups. Even so, there was still a distinct increase in the frequency of events involving environment change in the dementia patients. A significantly higher proportion of dementia patients had such life events in the six months preceding admission compared to the two control groups. This pattern remained when the analysis was restricted to independent plus possibly independent events, but was less noticeable when independent events alone were used. When only events that were also rated as having severe threat were included, the numbers of subjects experiencing life events was further reduced: although there was still a tendency for dementia patients to have experienced more life events with environment change, there were no longer any significant differences between the groups. A similar pattern was seen for environment change life events preceding deterioration (although the numbers were small). Environment change life events also increased the relative risk of admission for dementia sufferers.

### **Routine and environment life events in multivariate analysis**

Although there were apparent links between routine and environment change life events and both admission and deterioration, it was necessary to do multivariate



analyses in order to control for confounding factors. When multivariate analyses were applied, *independent* routine change life events were even more strongly associated with admission. This suggests that they contribute to the process of deterioration leading to an admission. Multivariate analyses involving environment change life events did not support the earlier finding that such events were more likely to occur in the dementia patient group.

Further logistic regression analysis showed that for all dementia sufferers depressive symptoms had a tendency to be associated with routine change life events occurring in the preceding six months.

Overall, the results show that life events occasioning routine change, and to a lesser extent life events with environment change, are important factors which may contribute significantly to the dementia sufferer's deterioration and increase the likelihood that they will be admitted to hospital. This supports findings from earlier studies looking at specific events such as relocation, which has an inherent component of routine and of environment change (e.g. Anthony et al., 1987a). Equally, studies have found that modification of existing environments, through renovation for example (Melin and Götestam, 1981; Stahler et al., 1984; Minde et al., 1990), or modification of routine by increased activities and therapy programmes (Morris, 1993), can improve symptoms, behaviour and functioning.



### **Life events and their actions in senile dementia**

Stressful (threatening) life events did not appear to be associated with admission. Although such events were more common in the dementia patients in the three months before a specified deterioration date, when dependent events were excluded the association was no longer significant. In the combined group of dementia sufferers, those who had experienced independent severe life events also had a greater degree of acute deterioration. Multivariate analyses suggested that severe threat events were not associated with deterioration and admission.

Routine and environment change appear to be different measures from threat. In dementia sufferers, routine change life events are strongly linked to both admission and deterioration. This indicates that routine is the principal element of life events which is responsible for the overall association. Environment change may be as important, but it is rarer and the associations are therefore less easy to demonstrate.

This study has served to produce convenient measures for quantifying changes in the individual's routine or environment. In addition, it has demonstrated that in dementia sufferers such changes may undermine functioning, resulting in deterioration and admission to hospital. This means that the results of the study supported the hypothesis stated in the second aim, i.e. *'deterioration in senile dementia is related to certain characteristics of life events in particular to associated change in the patient's social routine and perceptual environment'*. These changes do not appear to act instantaneously but rather destabilise the coping system and functioning.

This has important implications for clinical practice. Awareness of the effects of life events might enable mental health workers and carers of dementia sufferers to anticipate possible deterioration in response to changes in routine and environment. This allows for planning extra help and services before a crisis occurs which may precipitate an admission. The stress on the carer resulting from the life event or the behavioural decline in the dementia sufferer can then be contained. As well as helping to maintain the sufferer in the community, this ought also to minimise the distress and deterioration experienced.

One of the other principal findings of this study has been that life events are associated with depressive symptoms in senile dementia sufferers. This should not be unexpected since clinicians and lay people are equally aware that stress can produce affective symptoms. There are several implications for senile dementia sufferers. First, there has been a danger of dementia being regarded solely as a progressive degenerative disease, which therefore cannot be helped. Since depression can be treated, it is important to identify it in senile dementia sufferers. Secondly, the new awareness that stressful life events can cause depression in dementia sufferers will remind people that depression does occur in dementia and that mood symptoms are not necessarily all part of a biological process. Thirdly, it tells us about the aetiology of depression in senile dementia. Lastly, it emphasises that life stresses affect individuals with dementia, and in this way encourages fuller assessment of the social factors acting on them, as well as those acting on their carers. This is important because carers are likely to experience greater stress if patients become depressed, apathetic and unmotivated.



Such behaviour is upsetting as carers may not know what to do, and may feel inappropriately guilty, blaming themselves for the dementia sufferer's decline in mood.

In conclusion, both the threat and social environment aspects of life events are important, but in different ways. This has clinical implications which should help in the management of dementia sufferers. The findings also might shape preventative strategies to prevent admission, reduce acute deterioration, and identify and treat depression.

#### ***5.4.0 Deterioration and the mechanisms of admission***

##### **Acute deterioration and admission**

The new scale to measure acute deterioration in dementia sufferers was found to be reliable when used by novice raters after brief training. The reliability was satisfactory across the range of measures, including the key aspects of acute deterioration and presence or absence of life events. Where the Kappa was low, this was principally due to the small numbers of subjects with symptoms, or problems in certain areas. In these circumstances, samples can have high levels of agreement but low Kappa values (Feinstein and Cicchetti, 1990; Cicchetti and Feinstein, 1990). Further explanation of this phenomenon is given in section 4.4.0 of the results.

In addition, the acute deterioration score had concurrent validity for both raters, in that a high score was strongly correlated with the predicted likelihood of admission. Although the acute deterioration score alone did not accurately predict actual



admission, the fact that for both raters high deterioration was associated with likelihood of admission suggests that their evaluation of deterioration (including the score) was of importance in their decision-making process. This suggested that the score was a reliable and valid measure of deterioration and may be valuable in other studies seeking to quantify deterioration and investigate the decision making process leading to admission.

The raters were able to predict accurately admission on the basis of psychiatrist's letter (which had been carefully edited to remove details of the psychiatrist's decision-making process) in approximately 70% of cases. The few 'don't know' responses had been excluded. These results varied little when different diagnostic groups were examined. This suggests that the decision-making process to admit was remarkably consistent between two professionals with experience in old age psychiatry (a psychiatrist and a clinical psychologist), even when they only had access to the simple information contained in a standard assessment letter.

It would be interesting to replicate this study using other psychiatrists and clinical psychologists to see how similar the results were, whether a distinct pattern emerged, and whether the acute deterioration measures were still so strongly associated with the decision-making.

### **Decision making process and admission**

Comparing the two raters (DL & MO) with the original letter writer, there were similar patterns between all three for the factors stated as important in the decision to

admit. As expected, the vast majority of reasons for admission concerned the following: need for assessment, investigations or treatment; disturbed or unsafe behaviour; and risk of self harm. Respite was also seen as important, but not as the principal reason for admission. In this way the study met its fourth aim, which was *'to investigate the factors which were involved in the decision-making process leading up to an admission by way of an independent assessment of correspondence preceding admission'*.

### **Awareness of life events and likelihood of admission**

This analysis sought to identify whether awareness of life events by the assessing psychiatrist could independently influence admission. If this were the case, it might lead to elderly patients being admitted because of life events rather than because of deterioration in functioning and mental state. This in turn would suggest that the association of life events with admission might have been spurious due to factors other than an effect on deterioration.

Since the main study sought to identify possible links between life events, deterioration and admission, it was clearly necessary to use this aspect of the study to ascertain what proportion of events the psychiatrist had been aware of, and how awareness of these events might have influenced the decision to admit. Checking and rating the letters was a simple way of obtaining the information needed to carry out the analyses.

In the group of letters from the main study rated by DL, only a small minority (less than 10%) of the life events elicited at interview by MO were identified in the letter.



This suggests that the referrer was *unaware of the great majority of life events* and did not generally consider them in the process of making an assessment and decision about admission. Where life events were mentioned in the letter they did not increase the likelihood of admission. There was no evidence that life events influenced the assessing psychiatrist in favour of admission. It was also possible that because psychiatrists might view dementia as a purely organic disorder they do not elicit life events as part of their enquiry. Thus any association between life events and admission would therefore be more likely to come about through an effect on deterioration. This meant that the assessing doctor's knowledge and views (judged from the correspondence) preceding admission did not need to be taken into account when considering the results of the main study investigating the effects of life events in senile dementia.

There have been few studies of the reasons why elderly people with psychiatric problems are admitted. Hardy-Thompson et al. (1992) found that approximately 35% of general practitioners said a very important reason for requesting a domiciliary visit (DV) was that a DV facilitated admission, although there was no difference in the views of general practitioners with a high or low use of the DV service (Orrell et al., 1992a). There was, however, an indication that GPs with previous training in psychiatry were less likely to request DVs (Orrell et al., 1992a), and potentially were less likely to request admissions in general. These results give us an insight into the clinician's behaviour in relation to the decision to admit.



### ***5.5.0 Follow-up and prognostic factors***

This part of the study was very successful in that it obtained adequate data on all 60 patients followed up. At the time of follow-up, on average three years after admission, nearly half the patients had died. It is striking that although there was no difference in their physical health, there was a far higher death rate in those admitted to inpatient beds than in those admitted as day patients. Inpatient admission is a serious relocation, and relocation has been shown to be associated with higher mortality (Crank and Zweig, 1980; Anthony et al., 1987a; Harwood and Ebrahim, 1992).

In addition, only two (3.3%) of the original sample were living at home, the remainder either being dead or in some form of long-term institutional care (mainly nursing or residential homes). Again, inpatients had a far poorer prognosis than day patients, with a significantly higher proportion of them going directly into institutional care than being discharged home.

Attending a day centre after discharge from hospital did seem to be an important factor associated with lower mortality. It may be that those who went on to attend dementia day centres were actually fitter in the first place, but this is not supported by the results of the main Life Events in Senile Dementia study, which suggests that the dementia day centre controls were no more mentally or physically ill at the time of assessment than the dementia patient group. The results suggested that day centre attendance both before and after an admission improves survival and therefore might have positive effects on mental and physical health.

### **Prognostic factors**

Those who were still alive at follow-up had had a lower rate of life events in the six months preceding admission compared to those who had died, but at the 5% level this did not reach significance. There was also no relationship between life events and later use of institutional care. Likewise, life events with routine or environment change did not appear to influence survival or use of institutional care. In conclusion, life events of any sort occurring before admission did not appear to influence either mortality, survival, or use of institutional care.

The level of severity of dementia (in terms of cognitive impairment) was not significantly associated either with survival or with length of time in institutional care. While dementia patients with depressive symptoms had a higher mortality, this too did not reach significance, and there was no relationship between depressive symptoms and length of time in institutional care. However, anxiety symptoms were significantly associated with having a higher proportion of follow-up time in institutional care and showed a distinct trend towards an association with mortality.

The overall level of dependency (CAPE BRS score) did not appear to be linked with length of time spent in institutional care. However, there was a very significant association between a high CAPE score and death. In addition, the acute deterioration score did not predict mortality or time in institutional care, suggesting that it may not be useful in assessment of prognosis.



Social class and family relationships were not prognostic indicators, but certain aspects of support appeared to be linked with prognosis. Receipt of meals on wheels before admission (but not home help) was associated with a much higher mortality. This may be because receiving meals on wheels often indicated a lack of more personal support, since those with no help from relatives also had higher mortality. Day centre attendance prior to admission was associated with considerably reduced mortality, this clear trend almost reaching significance ( $p = 0.06$ ). Even more striking, was the strong positive association between *frequency* of day centre attendance prior to admission and increased length of survival.

#### **Multivariate analysis of factors associated with mortality**

Logistic regression analysis was used to select out factors significantly associated with mortality after controlling for the effects of possible confounding variables. Death was associated with: anxiety symptoms, higher CAPE score, receiving meals on wheels, and not attending a day centre prior to admission. Mortality was not associated with: type of admission (day or inpatient), age, sex, acute deterioration score, or support from relatives.

In a further multivariate analysis, duration of dementia was included as a variable. Mortality continued to be strongly associated with anxiety and meals on wheels, but was also associated with duration of dementia and female sex. The study had therefore satisfied its fifth aim which was to identify *'factors which predicted prognosis and service use in the dementia patients over a minimum of two years follow up period'*.



In summary, several predisposing factors appear to influence prognosis. As found in other studies, increased dependency was associated with poorer prognosis. This fits with the clinical experience of the more incapacitated patients tending to die earlier. Anxiety was linked with higher mortality in some dementia patients, which may reflect decompensation and adaptation difficulties in the face of new experiences (such as admission). Poor survival was also associated with receipt of meals on wheels, which may reflect isolation and lack of formal or informal social support. Dementia day centre attendance both before admission and after discharge seems to improve survival. This suggests that the facility should be more widely available because it appears to improve prognosis and should help maintain individuals in the community. The next section will discuss these findings in the context of previous research.

### ***5.5.1 Prognosis in senile dementia***

There has been little success in the identification of possible social or demographic factors affecting prognosis in Alzheimer's disease (Wilcock and Jacoby, 1991). In a one year follow-up of 212 psychogeriatric admissions, Katona et al. (1983) found no variables associated with outcome in the group suffering from dementia, whereas several factors predicted outcome in those with functional illnesses.

Few studies other than this have followed up patients for an appreciable period of time and examined the various psychological and physical factors which may be important in detail. In an early study, Bergmann (1977) found that cognitive function was a better prognostic indicator than other factors such as age, physical disability, social contacts or living conditions. Gamsu et al. (1990) in a six year follow up of 116

elderly women with senile dementia also showed that poorer cognitive function was associated with higher mortality. Other studies have also found cognitive impairment to influence survival (Burns et al., 1991; Drachman et al., 1991). Burns et al. (1991) reported that poor survival was also associated with male sex, increasing age, depression, longer duration of illness and physical ill health. In contrast, the current study (in the same catchment area and using some of the same instruments as Burns) found that female sex and duration of illness were associated with a worse prognosis but that physical ill health, age and cognitive impairment were not prognostic.

It is to be expected that increased duration of illness is associated with decreased survival, since as the dementia progresses the sufferer becomes progressively more mentally and physically incapacitated. Since cognitive impairment is a relatively good indicator of severity of dementia, one would also expect this to be linked with prognosis, as several studies have found. There are several possible reasons why cognitive impairment was not found to be associated with prognosis in this study. First, the number of patients may have been too small to show a difference. Secondly, the measure of cognitive function used (GMSS organic scale score) was relatively insensitive as it only produced a six point scale, whereas other studies have used far longer and more detailed indices of cognitive function (e.g. MMSE, CAMDEX) which would be more likely to demonstrate differences.

This study (like that of Burns) also suggested a link between depression and mortality, but the numbers may have been too small to show a significant result. Although anxiety is also an important problem for dementia sufferers (Kaplan and Sadock,



1988), many reviewers do not cover it (Wilcock and Jacoby, 1991; Alexopoulos and Abrams, 1991; Teri and Wagner, 1991) and in a recent major study of the various psychiatric symptoms in Alzheimer's disease it was not even reported (Burns et al., 1990). This study found that anxiety was linked with higher mortality, a link which persisted even when other variables were controlled for by using a logistic regression analysis. Since anxiety was very strongly associated with depressive symptoms it is possible that depressive symptoms might also have been associated with mortality if the sample had been larger. One of the main problems with many earlier follow-up studies is that data were analysed in over-simple ways (without multivariate analyses), and spurious results which were actually the effects of confounding factors may be reported as 'significant' associations.

In a study of patients with dementia admitted to a psychiatric day hospital, Bergmann et al. (1978) found that three-quarters were dead or in institutional care 12 months later. Poor outcome was associated with living alone or with spouses, and those living with younger relatives did best. Family support appeared to be the most important factor in maintaining the patient in the community, and the authors suggested that what was needed was increased help to families from social services. A later study (Bergmann et al., 1984) found that the quality of family relationships was also important, and a poor outcome at three months was associated with dementia patients who were less physically dependent and more dominant in their interaction with their relative. In the present study, the day patients appeared to have a much better prognosis than Bergmann's group, with only a third going on to institutional care at the end of their admission and only 40% being dead at follow-up three years later. The



better prognosis may explain why family support appears to have been less important in the current study, since over more prolonged periods of time it appears to be other services such as day centres which help maintain dementia sufferers in the community.

A higher CAPE score has been associated with poor outcome in a number of studies. Pattie and Gilleard (1978) found that the CAPE scale scores predicted whether or not acute elderly psychiatric patients would be discharged at three months after admission, and what their outcome was at two years. The BRS scale has proved particularly useful in assessing the feasibility of placement of patients in different hospital or social services settings. Bell and Gilleard (1986) studied 63 new admissions to a psychogeriatric day hospital and 40 new attenders at a day centre for elderly people with psychiatric problems, and followed them up six months later. They found that domestic situation, marital status and age were not significantly associated with outcome, whereas a high CAPE score remained associated with negative outcome after other factors were controlled for by discriminant function analysis. The present study also found that the CAPE BRS, a well-validated measure previously known to be associated with outcome, was also strongly associated with outcome in this study. This reconfirms the CAPE's usefulness as a predictor of outcome. This study, like Bell and Gilleard's, found that prognosis was not linked with support from relatives but was highly associated with CAPE BRS score. Attending a day centre probably meant that the dementia sufferers were less isolated and that they were less likely to need meals on wheels as they could have daily meals at the day centre. The day centre also provided stimulating and enjoyable activities which could improve mood and motivation. Home helps were useful in shopping for food and preparing meals.

However, they also often provided real social support, spending time with the person and keeping an eye on many other things crucial to maintaining someone in the community.

There are several implications to draw from these findings. First, they suggest that senile dementia patients needing psychiatric admission may do better as day patients, having a better survival rate and lower use of institutional care than inpatients. Secondly, after discharge comprehensive community support for patients including dementia day centres and home help, may improve prognosis and may even lower mortality. Thirdly, it confirms the value of the CAPE BRS scale as a predictor of prognosis, suggesting that it could be used more widely in clinical and social services assessments. Fourthly, although meals on wheels should not be considered as detrimental *per se*, the provision of them in a dementia sufferer who is barely coping might indicate the need for assessment and further input of community resources such as day care. Lastly, with the vast majority of senile dementia sufferers dead or in institutional care at follow-up three years later, the results show the poor prognosis overall. With the '*rising tide*' of very elderly in the population, this emphasises the need for adequate provision of community resources.

### ***5.6.0 Implications for future research on life events and senile dementia***

There are various ways in which the effects of stress on dementia may be studied. This particular study was limited in what it could achieve because of the need to combine methodological constraints with available resources. However, these limitations should not be over emphasised, as a new field of research has been opened up. The results of the current study and the theoretical issues discussed in the introduction confirm that research in this area merits expansion and development in the future.

The scope for future research will be discussed in the context of some of the potential methodological drawbacks of this study, each of which will be tackled in the forthcoming sections as listed below:

- Limited follow-up of dementia patients and no follow-up of control groups.
- Admission used as one index of deterioration.
- Measures of symptoms and behaviour taken at a single time point.
- More detailed assessment of cognitive function needed to assess links with life events and with prognosis.
- Need for measures of neuroendocrine function to address potential links between HPA axis, stress, and cognitive decline.
- Stress, neuroendocrine function, and the onset of dementia not investigated.



For a case control study (such as this one) the controls should be as similar to the subjects (dementia patients) as possible except in the key variable(s) which distinguish them. In this study the three samples were drawn from the same catchment area which suggests they should be reasonably similar. For example, if the dementia controls deteriorated they would be admitted to the same hospitals to which the dementia patients were admitted. Likewise, if the fit controls were to develop dementia they would have the same range of services available to them as the dementia groups. The catchment area, mean age, and sex distribution were no different in the three groups suggesting the control groups were reasonably well matched with the dementia patient group. However, there were a number of drawbacks with the control groups chosen. The dementia controls appeared to have dementia of an equivalent severity to the patients, however the duration of illness was somewhat longer in the dementia controls. In addition, dementia sufferers attending day centres may differ in some respects from other dementia sufferers in the community. Day centre attenders may be better supported by carers and other services, and their symptom or behaviour pattern may vary from that of a true epidemiological sample.

Although they were randomly selected from a general practice age/sex register and matched with the patients, the fit elderly sample appeared to be better off than either dementia group as evidenced by their higher social class and higher rate of home ownership. In higher social class couples and families it could be easier for dementia sufferers to move out of the area either to be closer to their relatives or to benefit from a better standard of living conditions and services. Nevertheless, social class did not appear to be a confounding factor in the multivariate analyses.

### **Limited follow-up of dementia patients and no follow-up of control groups**

It would have been useful to be able to interview all the informants and surviving patients at follow-up to enquire about life events in the interval, and to evaluate current levels of cognitive and behavioural function. This would have given a clearer idea of how life events might have affected mental state and prognosis. However, it was not possible to do this within the limited scope of this study. However, the author intends to do a follow-up similar to that in the dementia patients on the remaining 110 subjects (10 dementia patients, 50 dementia controls and 50 fit controls). This will enable comparisons to be made between the three subject groups with respect to prognosis in terms of institutionalisation, health, survival and mortality. In addition, the two dementia groups could be merged for comparison with the fit elderly controls. There are a number of questions to be answered, including: Do dementia sufferers attending a day centre have a better or worse prognosis than those who are admitted as psychiatric patients? Does anxiety predict poor prognosis in the dementia control group as it did in a dementia patient group? Does poor physical health, at initial assessment, predict poor prognosis?

### **Admission used as one index of deterioration**

As has been discussed, patients may be admitted for a variety of reasons including mental deterioration, psychosocial factors and physical ill health. To a large extent these have been controlled for in this study. In particular, the assessment-letter study effectively eliminates any suggestion of a link between psychiatrist's knowledge of life events and the likelihood of admission. However, a future study of the effects of life events in senile dementia would preferably have a large epidemiological sample



selected from a community survey (e.g. Livingston et al., 1990; O'Connor et al., 1991), which could then be followed up over time looking at life events periodically and measuring deterioration in cognition, behaviour and living skills. This would allow a more rigorous assessment of how life events might influence deterioration.

### **Measures of symptoms and behaviour taken at a single time point**

In the present study it was not possible to state categorically that mood disturbance followed life events because mood disturbance was not dated. Using a case control or epidemiological follow-up study would allow regular (e.g. yearly or six monthly) repetitions of measures of psychiatric symptoms and behaviour in a group of dementia sufferers. This would enable close monitoring of deterioration and analysis of possible factors such as life events. In addition, it would enable further assessment of the relationship between life events and depression, and life events and anxiety, to see if life events predicted the onset of depressive symptoms in dementia. This could be addressed because both life events and onset of mood symptoms would be dated; it would thus be possible to determine whether threatening life events had *preceded* mood disturbance.

### **More detailed assessment of cognitive function needed to assess links with life events and with prognosis**

In this study there was a suggestion that life events were more important in precipitating admission in subjects with milder dementia. In addition, prognosis did not appear to be linked with the severity of cognitive impairment, in contrast with the results of several other studies. Using a larger sample and more detailed instruments



to measure cognitive function (e.g. CAMDEX, Roth et al., 1986) would allow a clearer statistical examination of possible relationships between cognitive decline, admission, life events and prognosis.

### **Need for measures of neuroendocrine function to address potential links between HPA axis, stress and cognitive decline**

As hypothesised in the introduction, life stresses potentially affect the neuroendocrine system and neurotransmitters, which may be abnormal in senile dementia. It is therefore important to consider what measures might be useful. For example, metabolites of certain neurotransmitters, such as VMA, HVA, and 5-HIAA, can be measured in the cerebrospinal fluid (CSF), and reductions in HVA are associated with dementia (Soininen et al., 1981).

In addition, the dexamethasone suppression test (DST), which is an indicator of corticosteroid control mechanisms via the hypothalamo-pituitary-adrenal axis, is commonly abnormal in dementia (and depression). An abnormal DST indicates hypercortisolism and dysfunction in the ability to terminate the stress response and reduce corticosteroid levels. It has been shown that the ability to terminate the stress response may decline with ageing. Since the DST is frequently abnormal in both depression and dementia, it is potentially a predictor of the future development of these conditions. In a small study, Karlsson et al. (1988) found that reductions in serum cortisol were associated with improvements in cognitive function. Thus it may be important to do cortisol levels and the DST when assessing the potential relationship between stress and dementia.

The case control method has been used very successfully in the Oxford Project To Investigate Memory in Ageing (OPTIMA), in which approximately 300 subjects with dementia, (and a group of matched controls) are being followed up every six months from initial assessment until death (Jobst et al., 1992). In addition to a full initial assessment, the OPTIMA protocol includes cognitive assessment with the CAMDEX every six months, CT scan, SPET scan, lumbar puncture and blood samples once a year, and neuropathology at post-mortem. The addition of yearly DSTs and life event (LEDS) assessments would enable an in-depth analysis to be made of stress, neurochemistry, hypercortisolism and the course of dementia. It would also be possible to see if the DST predicted the onset of depressive symptoms in dementia. The study could also investigate whether the presence of an abnormal DST varies over time, or whether instead the hypercortisolism becomes more pronounced.

In the OPTIMA study it would be possible to match dementia patients with acute periods of deterioration with other dementia patients who had remained relatively stable, and to evaluate life events and hypercortisolism to see if either or both predicted deterioration and poor prognosis. Using the new measures of environment and routine described here, it would be possible to assess which characteristics of life events were associated with deterioration and poorer prognosis. Perhaps dementia patients with a higher level of support and services are less vulnerable to the effects of life events.



### **Stress, neuroendocrine function, and the onset of dementia not investigated**

The study of life events and stress in relation to the development or course of dementia is still at a very elementary stage. As has been discussed, there are many more questions than answers at the moment. One of the most intriguing possibilities which needs investigation is the potential link between ageing, stress, depression and the development of dementia (O'Dwyer and Orrell, 1994). A recent paper by Axelson et al. (1993) suggested a link between hippocampal volume measured by MRI scan and hypercortisolism in patients with major depression. This provided support for a role of the hippocampus in the neuroendocrine elevation of glucocorticoids in depression and in so doing emphasised the need for investigating the glucocorticoid cascade hypothesis in the development of the dementias such as Alzheimer's disease.

In order to address properly the question of the role of stress and hypercortisolism in the onset of dementia it would be necessary to study a large epidemiological sample of elderly people who were mentally fit at the commencement of the study. In addition to standardised assessments (such as the CAMDEX) and other investigations, each would have an initial DST (since it is abnormal in a proportion of healthy elderly) and a LEDS interview. These assessments could be completed annually, and after a certain number of individuals had developed dementia it would be possible to compare those with and without dementia to see whether the dementia group had abnormal DSTs and a greater experience of life events. Potentially, an abnormal DST might also predict the onset of depressive symptoms in fit controls or dementia sufferers.



### **5.7.0 Conclusions**

This is the first study to investigate how life events affect senile dementia using adequate methodology. Although admission in itself was not directly an index of deterioration, the measure of acute deterioration used was highly associated with admission. In any case, so little was known about the actions of life events on individuals with dementia that it was important to try and look at life events both before admission and before deterioration. This study appears to have done so satisfactorily, considering the various constraints upon it. In so doing it has established some of the theoretical and methodological foundations for further research.

The reliability between raters of the new measures of routine and environment change characteristics of life events has been established. A higher frequency of routine and environment change life events in the dementia patient group, before both admission and deterioration, indicates that these new measures may prove to be valuable in further studies in dementia and in other types of psychiatric or physical illness. Individuals with cognitive impairment may well be more susceptible to these aspects of life events, and it may therefore be fruitful to study mental handicap and other neuropsychiatric syndromes with respect to social environment change. It would also be interesting to study depression in the elderly, to compare the effects of threat and of social environment change (occurring as a result of life events).

Severe threat life events did not appear to be associated with admission *per se* in the dementia patients compared to the two control groups. However, those dementia patients who had datable acute deterioration had a higher frequency of life events in

the four weeks before deterioration compared to the two control groups. This excess appears to be principally due to dependent life events. However, the data suggests that in larger groups there might also be a significant excess of independent life events before an episode of deterioration in dementia sufferers.

The overall level of cognitive impairment and behavioural dependency at the time of assessment was similar in both the dementia patient and dementia control groups. However, the severity of deterioration was significantly greater in the dementia patient group. There was no association between severity of dementia (in terms of cognitive impairment and behavioural dependency) and life events. Although dementia patients who had life events had a higher mean score for acute deterioration than the dementia controls, this was not directly related to the occurrence of life events, but was simply due to their higher level of deterioration overall. Nevertheless, it is interesting to note that dementia controls who had life events in the three months before assessment tended to have higher mean acute deterioration scores than those dementia controls who had not experienced life events in that time. When the dementia groups were merged, independent severe life events were associated with higher deterioration scores, suggesting that life events might worsen deterioration.

In both dementia groups, severe (and independent) life events appeared to precipitate depressive symptoms. No association was found in the fit elderly, but this is predictable since those with depressive symptoms had been screened out. In the dementia patients, life events also appeared to be associated with anxiety symptoms. This suggests that when individuals with dementia suffer a life event and are also



admitted to hospital, they become vulnerable to the development of anxiety symptoms. There are, of course, practical problems in evaluating mood symptoms in patients with dementia. It is possible that in some cases the affective symptoms may have occurred before the onset of the life events, although for this to be the case the symptoms would have had to continue for very many months. Because of their memory problems, the dementia sufferer's account of when symptoms started could not be accepted as accurate. However, there would also have been problems with using an informant's account of mood symptoms, since these are often remarkably inconsistent with psychiatric assessments of whether or not the patient is depressed (Burns et al, 1990). Potential solutions to this problem have been discussed in the section on future research.

Having discussed the methodological difficulties in this study, it should still be emphasised that the finding of threatening life events being associated with depressive symptoms in dementia sufferers is of considerable importance. As Förstl et al. (1993) have pointed out, although it is not yet possible effectively to treat cognitive impairment in dementia, other psychiatric symptoms such as depression may be more amenable to treatment and when alleviated may result in an improved quality of life and well-being for dementia sufferers and their carers. Equally, psychiatrists working with the elderly need to be aware that senile dementia sufferers find life events with routine and environment change confusing, and this may result in decompensation, deterioration and admission. The clinical implications of this are that such events should be kept to a minimum in order to try and help maintain the individual in the community. When such events occur, additional support for the patient and carer may



be necessary in order to offset the effects of the events and help the support system cope. For example, a community psychiatric nurse may help the carer to cope with the strain of disturbed behaviour, or a sitting service could allow the carer to get out of the house and have a break, to do things such as shopping or social activities.

In the follow-up study, those who were admitted as in-patients generally had a worse prognosis in terms of institutional care and survival compared to those dementia patients who were admitted as day patients. Life events before admission did not appear to be associated with prognosis. This also held for the life events with routine or environment change. However, a slightly higher proportion of dementia patients who had had a life event in the previous six months had died compared to those without life events. There was no association between cognitive function and prognosis, but dementia patients with depressive symptoms and those with anxiety symptoms were more likely to be dead at follow-up compared to those without such symptoms. In addition, those with anxiety symptoms were more likely to have spent a higher proportion of the follow-up period in institutional care. Mirroring the results of earlier studies, a higher level of dependency on the CAPE score was associated with poorer prognosis in terms of a higher mortality rate. The acute deterioration score appeared to be slightly correlated with poor prognosis in terms of length of time spent in institutional care. Unlike an earlier study (Bergmann et al., 1984), family relationships did not appear to influence long term prognosis. However, those receiving meals on wheels had a poor prognosis, whereas those people attending a day centre tended to do better, as did those who received some degree of support from relatives. When other variables were controlled for, symptoms of anxiety, high CAPE

score, and provision of meals on wheels were all significantly related to higher mortality, whereas day centre provision was associated with a lower mortality rate. This supports findings of other studies which suggest that appropriate mental stimulation and activity improves prognosis in dementia (Katzman, 1993), and suggests that the results of the follow-up of dementia controls will be interesting.

The results indicate that for dementia sufferers the particular characteristics of life events may be relatively specific in their effects. Life events with severe threat appear to cause depressive symptoms, whereas life events with social environment change precipitate deterioration and also lead to admission. This has implications for our understanding of the effects of social factors in senile dementia. Further research might enable us to develop a more coherent framework of how stress affects dementia sufferers and what preventative strategies may be developed to prevent symptomatic deterioration, improve their quality of life, and to maintain them in the community.



# APPENDIX

## 7.0.0 References

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### ***7.1.0 Protocol for life events in senile dementia study***

## **RESEARCH PROPOSAL - LIFE EVENTS IN SENILE DEMENTIA**

### **INTRODUCTION**

In senile dementia, acute episodes of cognitive and behavioural deterioration cannot easily be explained by conventional biological models of the dementing process. Dementia patients are sensitive to changes made in their ward routine and environment (1,2,3). Relocation can lead to disorientation and behavioural disturbance (4) and even an increase in mortality (5). Life events contribute to the onset or relapse of psychiatric illness (6,7,8) and have also been linked with decline in physical health or even death (9,10,11). Since senile dementia patients are sensitive to changes in their routine and environment they may be vulnerable to life events which could also cause distress. These factors may result in the patient's coping skills being overloaded leading to a deterioration in cognition, mood and behaviour necessitating hospital admission.

In a pilot study, 25 day or in-patients admitted to a psychogeriatric unit and their relatives were interviewed to assess their life events prior to admission. The comparison group consisted of fit, elderly subjects from a local general practice, who had been randomly selected but matched for age and sex. Data collected were the same as in the full study (i.e. GMSS, CAPE, LEDS etc.). Initial results of the GMSS were analysed using the AGE CAT computer program to rate severity of organic symptoms. The patient group had a total of 37 severe life events during the six months prior to admission whereas the control group only experienced 16 severe life events in all. In the period between 3 and 6 months before admission 11 patients had experienced a severe independent life event compared to only 3 controls who had ( $p < 0.025$ ). The new scales of routine and environment were found to be highly reliable when used by new raters after brief training (12). The pilot study thus established the feasibility of this method and a preliminary corroboration of the hypothesis.

### **AIMS**

- 1) To investigate the hypothesis that recent life events are related both to acute deterioration of senile dementia and the patient's presentation to services.



2) To investigate the hypothesis that certain characteristics of life events are particularly related to such deterioration, with reference to any associated change in the patient's social routine and perceptual environment.

3) To develop new scales to measure changes in social routine and perceptual environment occasioned by life events.

## METHOD

The study will be a case-control comparison. A group of patients with senile dementia and their informants will be interviewed about life events occurring over the six months prior to their admission to a psychogeriatric assessment unit, (or three months prior to their deterioration, whichever is the furthest back in time). Two control groups (a & b) of elderly people in the community and their informants will also be interviewed about life events during the previous six months. The patients and controls will be interviewed using the GMSS and LEDS.

### Study Group:

70 patients with dementia, age 65+, admitted to a psychogeriatric assessment unit in the previous four months.

\* Inclusion Criteria - 1. Consultant diagnosis of primary dementia plus a score of less than 24 on the Mini Mental State examination which is the best cut off point for differentiating between dementia and non-organic psychiatric illness (13), 2. Suitable informant, 3. No other psychiatric admissions in last year, 4. Absence of severe physical illness.

### Control Groups:

(a) 50 elderly subjects, matched for age and sex from the register of a local group general practice.

\* Inclusion Criteria - 1. No psychiatric illness, 3. & 4. as above.

(b) 50 elderly subjects with primary dementia in the community.

\* Inclusion Criteria - 1., 2., 3. & 4. as above, 5. No episodes of significant mental deterioration in past six months.

Control Group a) provides a comparison of the rate and qualities of life events in the normal community elderly, which will show the baseline level of life events in a matched population. Control Group b) measures the rate and qualities of life events in a community elderly group with dementia who have been psychiatrically stable for the preceding 6 months.

**Informants:**

A close friend or relative either living with the subject or in regular contact at least weekly and able to give an accurate account of the subject's life events over the six months prior to deterioration or, in the case of controls, to interview.

**Instruments:**

**Geriatric Mental State Schedule (GMSS)**

This is a semi-structured clinical interview for the assessment of diagnosis and mental state in the elderly (14). It can identify cases and provide a reliable diagnosis, and can be analysed using the AGE CAT computerised diagnostic system.

**Bedford College Life Events and Difficulties Schedule (LEDS)**

This is a method of identifying and gathering relevant information on life events and difficulties using a semi-structured interview (6). Events will be rated according to the degree of 'threat' and 'independence' using the contextual rating method of Brown and Harris.

**Clifton Assessment Procedure for the Elderly (CAPE)** (behavioural assessment schedule). This is a standard method for assessing behavioural functioning.

New scales have been developed to score changes in routine and in environment on the LEDS (12), and assessments will be made of the extent to which events implied a disruption of the care or support the elderly person was receiving from family, friends or support services.

Standard demographic data such as age, sex, social class, family and social network and social situation, will also be collected, as well as information on the other residents, home environment, and level of social support.



### **Assessment of 'Acute Deterioration':**

Elderly patients may be admitted to hospital for physical, psychiatric, or social reasons. Often several factors influence the decision to admit as a day or inpatient. In order to take these into account the data collection includes ratings for deterioration in physical health, family and social factors, and life events. During the interview with the informant, psychiatric deterioration is rated on a number of scales including cognition, self care, mood and behaviour, and care will be taken to date this accurately. The analysis will be able to control for high and low degrees of psychiatric deterioration prior to admission.

As a further assessment of the factors leading to admission, the psychiatric correspondence prior to the admission will be rated independently by an observer blind to the outcome to determine the relative influences of physical, psychiatric, and social factors on the decision of the GP to seek help. The observer will also look for any life events noted in the correspondence. This is to control for any knowledge of such events that may have influenced the referrer's decision making process.

### **Procedure:**

Patients will be interviewed in hospital, and controls will be interviewed at home. Informant interviews will be conducted at home wherever possible. Patients will be obtained from the Felix Post Unit and Gresham 1 Ward. Current trends indicate 35 suitable cases per year from these two units. Permission has been obtained from the three consultants with psychogeriatric beds for the inclusion of their patients in the study.

Controls (a) will be obtained using random number tables to select from an age/sex register of a local general practice, this will continue until appropriate matches were identified for all the patient group. The Forest Hill Practice has agreed to provide the controls it has an age/sex register, and a large (20,000+) socially mixed population with a catchment area similar to that of the patient group. This makes it an ideal sample to draw the control group from.

Control group (b) will be recruited from a variety of sources in the local catchment area to provide a group with a similar age, sex and severity of dementia profile to the

other two groups. Subjects will be obtained via day centres, outpatient clinics and the local general practice.

The researcher will carry out all aspects of the study except where supervision or independent assessments are required. The combination of prior training, experience and knowledge of the field makes him most suitable to carry out the full study.

Ethical Committee approval has been granted (Bethlem Royal and Maudsley Hospitals and the Institute of Psychiatry - Ethical Committee).

### LOGISTICS

#### Training:

Trained in the use of the GMSS by Dr Forshaw from the Institute of Psychiatry. He is a recognised trainer and worked with Professor Copeland on the schedule. Trained in the use of LEDS by Dr Bebbington. Currently receiving supervision in statistics from Professor Everitt.

#### Experience:

Worked as registrar to Dr Bergmann on the Felix Post Unit. This provided important experience of working with psychogeriatric patients and the associated multidisciplinary team. From 1.4.88 to 30.9.88 did the Maudsley research registrar post with Dr Bebbington attached to the MRC Social Psychiatry Unit. During this time completed the data collection for my M. Phil. project (25 patients and 25 controls). M.Phil registration upgraded to Ph.D. Experienced in use of SPSS.

#### Duration:

Each assessment requires approximately two hours which includes time for travelling and administration. Data collection is continuing part-time (one day per week). Estimated time to complete data collection six to nine months. Estimated time to analyse results and write up project as Ph.D - six months.

Facilities: Currently attached worker at the MRC Social and Community Psychiatry Unit, Institute of Psychiatry.



## RESULTS AND ANALYSIS

Initial results (on first 25 of each) have been coded onto computer disc and the GMSS results analysed using the AGECAAT computer program to rate severity of organic symptoms. The results will be subjected to non-parametric tests (e.g. chi-squared).

Comparisons will be made with respect to life events between the study and control groups according to: Severity/Stressfulness, Independence, Change in Environment and routine. Power analyses suggest that if the control group has a true life event rate of 20% and the case group has a true life event rate of 40%, a sample size of 50 per group gives a 95% chance of demonstrating this difference at the  $p < 0.01$  level.

**IMPLICATIONS** - The pilot study suggests that life events precede an episode of deterioration of senile dementia which leads to a hospital admission. The analysis of the results of the full study should indicate if changes in the routine and environment which could impair cognitions and behaviour and so functioning, could account for any deterioration leading to admission. Awareness of any connection might permit such deterioration to be avoided if the patient could be given more social support or their coping skills could be enhanced by using particular strategies. This in turn might mean that the patient could be supported at home instead of being admitted to hospital. Therefore, the implications of this study would be; at least an understanding of the social influences on dementia which are a much neglected field of research, and at most a clear link between life events, deterioration and admission which suggests interventions which may prevent acute deterioration leading to admission. The results will be written up as research papers and submitted to peer refereed journals.

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### 7.1.1 Data package - main study

#### MAIN STUDY - DATA PACKAGE

1. Front Sheet
  - 2-3. History of presenting complaint and acute deterioration. Other historical details. Social situation, services and support.
  - 4-6. GMSS Demographic data. Open questions.
  - 8-11. GMSS Rating sheets.
  12. Life events - (Informant report).
  13. Life events - (Subject report).
  14. CAPE Behavioural rating scale
- 

PROJECT NUMBER PROJ \_ \_ \_

Checklist - tick all for inclusion -

- Admission < 4/12
- No other psychiatric admissions in last year
- Suitable informant
- Consultant diagnosis Primary Dementia (specify) DEM \_
- Appropriate score on cognitive scale (specify) /
- No excluding severe physical illness (e.g. stroke , major infection)
- Consent obtained

Yes/abnormal = 1      No/normal = 0      Unclassified = 9

Date of birth ..... AGE \_ \_

Male = 1, Female = 2      SEX \_

Date admitted ..... DTAD \_ \_ \_ \_ \_

Date entered study ..... DTEN \_ \_ \_ \_ \_

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Family History - ? dementia , ? psychiatric , ? alcohol

dementia - parents      DEMP \_

dementia - siblings      DEMS \_

alcoholism - 1st deg.rel.      ALCO \_

other psych. illness 1st deg. rel.      PSYR \_

Personal History - ? education standard ..... EDUC \_

Occupations - ..... SOCL \_

Physical Illness - ? Medical, ? Injury, ? Surgery, ? Admissions

Past / Present  
3 = Severe, 2 = Moderate, 1 = Mild

Cardiovascular	CVS	_	/	_
Respiratory	RESP	_	/	_
Neurological	NEUR	_	/	_
Neoplastic	CARC	_	/	_
Metabolic/Endocrine	MEND	_	/	_
Infective	INFE	_	/	_
Bone/Joint/Muscle	BOJM	_	/	_

Recent disability due to physical illness PHYD \_  
4 = Extreme, 3 = Severe, 2 = Moderate, 1 = Mild, 0 = Nil

Past Psychiatric Illness - ? Treatment, ? Admissions.

Dementia Yes = 1 No = 0	DEMA	_
Other	PSYA	_
Alcohol abuse	ALCO	_

### Social Situation.

Type of accomodation ACCO \_ \_

1 = Own House, 2 = Own Flat, 3 = Rented House, 4 = Rented Flat,  
5 = Council House, 6 = Council Flat, 7 = Sheltered Flat,  
8 = Residential Care, 9 = Unclassified, 0 = Other.

### Condition of home

Structural 0 = good, 5 = extremely dilapidated	STRU	_
Superficial 0 = good, 5 = extremely dirty/neglected	SUPE	_

Support Services: level of support provided by each

4 = Full, 3 = Major, 2 = Minor, 1 = Contact only.

Home Help	HELP	_
Meals on Wheels	WEAL	_
Day Centre	DAYC	_
Social Worker	SOCW	_
District Nurse	DIST	_
CPN	CPNU	_
Voluntary Worker	VOLW	_
Relatives	RELI	_
Other	OTHR	_

Average number of contacts during week: WD \_ WE \_ WEEC \_ \_  
WD = per day weekday, WE = per day weekend



Informant:  
1 = Spouse, 2 = Son, 3 = Daughter, 4 = Brother, 5 = Sister,  
6 = Other relative, 7 = Friend, 8 = Warden/Other. INFO \_

Co-Habitees ? COHA \_ \_  
Upto two coded as above

Quality of relationship with informant ADOS \_  
BCON \_  
CPHD \_

Date of onset of illness ..... DTON \_ \_ \_ \_ \_

Date of onset of acute deterioration ..... DTAD \_ \_ \_ \_ \_

**Deterioration in :**

3 = Severe, 2 = Moderate, 1 = Mild, 0 = Nil:

Mood - Irritable / Suspicious	IRSU	_
- Depressed / Withdrawn	DEWI	_
Behaviour - Restless / Wandering	WAND	_
- Aggressive / Disinhibited	AGDI	_
Cognition - Memory / Disorientated / Confused	COGN	_
Self Care (personal hygiene and appearance)	SELC	_
Sleep Pattern	SLEP	_
Continence	CONT	_
Other	OTHE	_

History of presenting complaint :

FAMILY TREE

LIFE EVENT RATING SHEET

Details of events

LIFE EVENTS : DEGREE OF THREAT = T  
LEVEL OF INDEPENDENCE = I  
CHANGE IN ROUTINE = R  
CHANGE IN ENVIRONMENT = E  
DATE OF EVENT see below

Environment and Routine rated :

4 = Extreme change, 3 = Severe, 2 = Moderate, 1 = Mild,  
0 = No change.

Events rated		Date Event									
		N	O	T	I	R	E	DAY	MON	YR	
	EVEA	-	-	.	.	.	.	-	-	-	.
	EVEB	-	-	.	.	.	.	-	-	-	.
	EVEC	-	-	.	.	.	.	-	-	-	.
	EVED	-	-	.	.	.	.	-	-	-	.
	EVEE	-	-	.	.	.	.	-	-	-	.
	EVEF	-	-	.	.	.	.	-	-	-	.
	EVEG	-	-	.	.	.	.	-	-	-	.



### ***7.1.2 Manual for data package***

#### **LIFE EVENTS IN SENILE DEMENTIA - MANUAL FOR DATA PACKAGE:**

This does not include details on G.M.S.S., L.E.D.S., or questions on quality of relationship, refer to appropriate sources.

---

For inclusion in the study dementia sufferers must have scores in the cognitively impaired range (see below) on one of the cognitive scales (Orrell et al., 1992):-

MINI-MENTAL STATE EXAMINATION (23 points or less out of 30)

FELIX POST UNIT SCORE (14 points or less out of 20)

ABBREVIATED MENTAL TEST SCORE (7 points or less out of 10)

---

#### **'Excluding physical illness'**

This covers any disorder which significantly affects the adequate functioning of the brain in terms of cognitive and intellectual powers. This would cover any other dementia (which is not primary degenerative in origin e.g. alcoholic dementia, hydrocephalus, stroke), delirium, and any physical illness causing impaired consciousness or cognitive impairment. This is necessary to ensure a homogeneous group of dementia sufferers with primary degenerative dementias in the study.

---

#### **CODE:**

#### **DEFINITION:**

PROJ Project number for subject - study or control

DEM Rate for which type of primary dementia; 1 = Alzheimers,  
2 = Multi-Infarct, 3 = Mixed (1+2), 4 = Other (e.g. Pick's Disease, Parkinson's disease, Huntingdon's Chorea)

AGE Age on date of entry to study.

(SEX, DTAD, DTEN, DEMP, DEMS, ALCO, PSYR, see rating sheet)

EDUC Educational level , 1 = Degree or diploma, 2 = Trade training or apprenticeship, 3 = Left school at 14 and Standard 7, 4 = Left school before 14 or less than Standard 7.

**SOCL Social Class defined by principle occupation before retirement (according to social class directory)**

**1 = Professional, 2 = Managerial, 3 = Skilled, 4 = Semi-skilled, 5 = Unskilled.**

**If married - not in full employment define by spouses job.**

**Physical Illness:**

**Severe = Possibility of a real threat to life AND/OR resulting in severe disability or discomfort.**

**Moderate = Significant threat to physical well being AND/OR resulting in moderate disability or discomfort.**

**Mild = No significant disability, mild discomfort AND/OR latent physical threat.**

**Past Psychiatric Illness:**

**Note any details but only score for previous admission or not.**

**Social Situation:**

**Support services; level of support provided, is defined according to each specific service i.e. Rating 'full' for RELI (relatives) would mean the subject required close supervision by a cohabitee relative who probably received not much help from other sources. Rating 'full' for a day centre would be an attendance of 5 days per week. On the other hand a community psychiatric nurses (code CPNU) should be rated 'full' for daily visits and assistance, whereas a 'minor rating' would do for visits weekly or less.**

**Page 3 comprises data predominantly derived from the informant:**

**For rating contacts WD = no. per weekday, WE = per weekend day and WEEC = total per week - Score 1 for any visit or upto an hour contact and add up.**

**For ratings of deterioration one obviously needs to take into account the previous level of functioning and it will be necessary to write full details under the space for history of presenting complaint. For instance, if someone has always tended to be suspicious then a slight increase in this may only merit a 'mild' rating. A more pronounced increase especially if it affected their behaviour could justify a 'moderate' or even a**



'severe' score. On the other hand, a person who was previously not suspicious or irritable but became noticeably so in the course of their deterioration may require a 'severe' rating. Thus the degree of change and decline in function must be taken into account.

---

Page 12/13 relate to rating of life events:

The life events listed have already been rated with respect to degree of threat and level of independence to the subject.

Threat rated as        'marked threat' = 1  
                              'moderate threat' = 2  
                              'mild threat' = 3  
                              'no threat' = 4

Independence rated as        'independent' = 1  
                                      'possibly independent' = 2  
                                      'dependent' = 3

### ***7.1.3 Assessment of quality of family relationships***

#### **Notes on rating**

##### **1) Source of data:-**

A Dominance-submissiveness :-	(i) Social work account (ii) Patient's history
B Control system	(iii) Psychiatric interview with relative
C Physical dependency	(i) O.T. assessment (ii) Physiotherapy assessment (iii) Social work account (iv) Medical notes

2) Ratings are to be made as at the time the case presents, although information becoming apparent after that time can be used.

---

#### **A. Dominance-submissiveness in a particular relationship**

1. Patient controls every area of a relationship.
2. Patient generally in control but relative able to set some limits.
3. Patient mainly in control but there are some areas where the relative has a lot of control.
4. Equal sharing of control; balance of power or independence.
5. Relative mainly in control but there are some areas where the patient has a lot of control.
6. Relative generally in control, but options left in some areas to the patient.
7. Relative controls every area of a relationship.



### **B. The Communication System in a particular relationship**

1. Constant negative communication by punishing, hurtful criticism or by withdrawal. Some physical aggression.
2. Frequent verbal aggressiveness or withdrawal from the relationship. Little reward for the partner in the relationship.
3. A lot of punishment used - verbal or in the form of withdrawal, but some reward in the relationship.
4. Equal amounts of negative verbal communication/withdrawal and warm positive communication.
5. Mainly warm positive communication but some negative verbal communication or withdrawal also.
6. Predominantly warm positive communication but occasional negative verbal communication in the relationship.
7. Almost continual positive reward system: devoted, loving, almost no cross words or withdrawal from the relationship.

### **C. Physical dependency - Autonomy in a particular relationship**

1. Relative gives patient a great deal of basic physical care each day e.g., dresses, washes, feeds, toilets, etc.
2. Relative gives patient some daily help with shopping, cooking, cleaning etc. although the patient is independent in self care from day to day.
3. Relative gives patient some help from time to time (less than daily) with cleaning, cooking shopping, bathing etc.
4. Patient and relative are completely independent of each other in terms of day to day living activities, or give each other equal amount of help.
5. Patient gives relative some help from time to time (less than daily) with cleaning, cooking shopping, bathing etc.
6. Patient gives relative some daily help with shopping, cooking, cleaning etc. although the relative is independent in self care from day to day.
7. Patient gives relative a great deal of basic physical care each day e.g., dresses, washes, feeds, toilets, etc.

### ***7.2.0 Guidelines for rating change in environment or routine***

'Change in routine' and 'change in environment' are new scales applied to each life event which need some elaboration. Please rate the life events listed for each subject according to the guidelines below. Together they are designed to measure the impact of a life event on an individual's daily life. Certain life events may be judged to have no direct relationship to daily life, but may still be independent and involve a high degree of threat. An example of this could be the death of a sibling with whom the subject now has little or no regular contact except by letter or telephone. Such an event would involve a 'threat' but no change in the subject's regular routine or immediate environment. Routine and environment therefore, are aspects which measure the disruption to daily life in relation to the effect of a life event. This disruption is distinct from the 'threat' attributable to a life event since routine and environment are quite different qualities. In addition, disruption to the individual's daily life (in terms of change in environment or routine), may occur without a life event, just as a life event may occur without associated changes in environment or routine. Change in routine (R) is primarily concerned with personal contacts in the subject's day to day life such as regular visitors. These would Home Help or any other support staff such as a Warden . If one of these key people stopped attending through illness or change of job etc. it would constitute a routine change the severity of which would be determined by their relationship to the subject and the contribution to the subject's routine. Regular structured activities outside the home such as attendance at a day centre or luncheon club should also be rated.

#### **Routine Change - EXAMPLES AND RATING SCALE**

4 = Extreme - Permanent loss of carer living with subject.

3 = Severe - Loss of carer attending 3 or more days per week or closure/loss of day centre. Duration - two weeks or more.

2 = Moderate - Loss of carer or visitor attending 1 or 2 days per week or loss of days attendance at a day centre. Duration - one month or more

1 = Mild - Loss of any other visitor/carers/friend with whom the subject has regular contact (weekly). Duration - one month or more.

0 = No change in routine



Changes in environment (E) could be either external or internal, in relation to the subject's home circumstances. External changes might involve a move, a holiday etc.. Internal changes might relate to structural damage, or repairs to the house. If the subject regularly spent a substantial proportion of the week in another place such as a day centre or someone else's home (e.g. a relative's) then a change in this could also be regarded as a change in environment, the rating of which would depend essentially on the time spent there. Sometimes changes in environment and routine will occur together. For example the closing of a day centre which the subject had been attending.

#### **Environment Change - EXAMPLES AND RATING SCALE**

- 4 = Extreme** - Moving to worse accommodation or a new area unknown to subject
- 3 = Severe** - Any other permanent or long term move (one month or more)
- 2 = Moderate** - Temporary move e.g. holiday, respite care, hospitalisation, or stay with relatives, for more than three days and less than one month
- 1 = Mild** - Changing to a different room in the home. Major structural alteration or damage in the home. Loss of regular visiting to another environment (for example day centre), for one month or more.
- 0 = No change in environment**

Although these are the guidelines the rater's discretion should be used in cases where the rating of degree of routine or environment change is difficult to classify

#### ***7.2.1 Examples of rating change in environment or routine***

These examples were used in the training package used to train naive raters. The raters were first shown several examples which were discussed. They were then given several events to rate these were checked and discussed and final ratings were agreed with the trainer (MO). Following this they were given 30 events to rate independently using the guidelines for scoring events.

#### **EXAMPLE A**

87 year old lady who lives alone in a rented flat. Her left leg was amputated 10 years ago and she gets phantom pains. Her son lives nearby and sees her every weekend. She has a home help twice a week but otherwise has little social contact.

### **Life Event**

An elderly lady who had been a close friend of hers for many years wrote to say that she had found out she had cancer of the bowel and would not be able to take a holiday because of it. Although they kept in touch they did not see each other regularly.

Severe threat

Independent

No change in environment (  $E = 0$  )

No change in routine (  $R = 0$  )

### **Life Event**

She had to go into hospital for five weeks for investigation of the phantom pains. No particular cause or improvement in treatment was found.

Moderate threat

Independent

Moderate change in environment (  $E = 2$  )

Mild change in routine (  $R = 1$  )

### **EXAMPLE B**

78 year old lady who lives in an old peoples home. She had broken her leg after a fall earlier in the year and had to spend 5 weeks in hospital. She also suffered from congestive cardiac failure. Her daughter visited her every 3 weeks.

### **Life Event**

She burnt her leg on a radiator and had to spend 3 weeks in a burns unit.

Moderate threat

Dependent

Moderate change in environment (  $E = 2$  )

Moderate change in routine (  $R = 2$  )

### **EXAMPLE C**

92 year old lady who lives in a sheltered flat. She is quite well physically. Home help attends twice a week and meals on wheels 3 times a week. She sees her daughter every six weeks.



**Life Event**

An elderly lady (91) who had been a close friend for 43 years died. She used to see her every Sunday, and until her friend moved out of the area they saw each other daily.

Severe threat

Independent

No change in environment (  $E = 0$  )

Mild change in routine (  $R = 1$  )

**EXAMPLE D**

73 year old man who lives with his daughter and son in law in their house. He is physically quite well.

**Life Event**

His son came back unexpectedly from a trip to the West Indies. He had severe ulcers and sores on his feet which were also markedly swollen. He had to receive specialist treatment.

Moderate threat

Independent

No change in environment (  $E = 0$  )

No change in routine (  $R = 0$  )

**Life Event**

His son in law moved out because of family difficulties. As a result of this the subject's daughter had to take on extra work to earn more money.

This meant she was out nearly all day and spent much less time with her father.

Severe threat

Possibly independent

No change in environment (  $E = 0$  )

Severe change in routine (  $R = 3$  )

**For reasons of space the not all life events used in the training and the inter-rater reliability study have not been illustrated here.**

### ***7.3.0 Protocol for assessment letter study***

#### **PSYCHIATRIC ASSESSMENT IN THE ELDERLY - Protocol:**

##### **Introduction:**

With the elderly population increasing and the consequent need for psychiatric services for the elderly to expand, it is important to evaluate the decision making process leading to admission as compared to support in the community. If admissions are sometimes precipitated for reasons other than clinical need, then this should be identified and discussed. Likewise if certain psychiatric symptoms are more likely to result in admission perhaps research and clinical efforts should focus on more on methods to cope and help carers cope with those symptoms in the community.

##### **Aims:**

To examine correspondence prior to admission in order to identify factors which are associated with an increased risk of admission for elderly psychiatric patients.

To compare the information derived from a preliminary assessment with that derived from a full day patient or inpatient psychiatric assessment in order to determine the initial assessors knowledge of the patient's deterioration, social circumstances and prior life events.

##### **Method:**

For 120 elderly psychiatric patients the specialist assessment letters to the general practitioner will be examined and rated with respect to the following details:

Educational background

Social class

Physical illness

Psychiatric history

Accommodation

Social support

Recent life events

Deterioration in psychiatric symptoms

The letters will be drawn from the following sources a) 50 from a study of life events in senile dementia, b) 70 from a study of domiciliary visits by old age psychiatrists.



The primary rater (DL) will undergo training in the rating by a researcher (MO) who is familiar with the use of the ratings package. This will involve a discussion and clarification of the protocol and rating guidelines followed by joint ratings and discussion of 10 cases drawn from the total pool (170).

After this training period the primary rater and researcher will each independently rate 30 cases to assess adequate reliability for the core measures. Assuming reliability is adequate, the primary rater will go on to rate the remaining cases. Apart from the initial training period the primary rater will be blind to whether or not the patient was admitted as a result of the assessment. The rater will be asked to judge the likelihood of whether or not the patient was admitted as a result of the assessment and which factors in the assessment were most likely to precipitate admission.

The primary rater (DL) is a researcher and clinical psychologist experienced in working with the elderly. The researcher (MO) is an academic psychiatrist working with the elderly. Both have experience and training in the use of the LEDS to assess life events.

**Results:** The results will be subjected to appropriate statistical tests.

**Implications:**

The results may have implications for how old age psychiatrists make decisions about admission and suggest useful foci for research and interventions for elderly patients to be maintained in the community.

### 7.3.1 Data package for assessment letter study

CODE 1 = YES/ABNORMAL, 2 = NO/NORMAL, 9 = UNKNOWN

Letter Number LETNO \_ \_ \_

Family History : dementia - parents DEMP \_  
 dementia - siblings DEMS \_  
 alcoholism - 1st deg.rel. ALCO \_  
 other psych. illness 1st deg. rel. PSYR \_

Education standard ..... EDUC \_

Occupations - ..... SOCL \_

Physical Illness - ? Medical, Injury, Surgery, ? Admissions  
 3 = Severe, 2 = Moderate, Past/Pres.

1 = Mild, 0 = No problems

Cardiovascular	CVS	-	/	-
Respiratory	RESP	-	/	-
Neurological	NEUR	-	/	-
Neoplastic	CARC	-	/	-
Metabolic/Endocrine	MEND	-	/	-
Infective	INFE	-	/	-
Bone/Joint/Muscle	BOJM	-	/	-

Present physical illness indicates problem in the last 3 months. If letter has mentioned physical health at all assume ratings 0 unless problems specifically noted.

Recent disability due to phys. illness (mobility) PHYD \_  
 4 = Extreme, 3 = Severe, 2 = Moderate, 1 = Mild, 0 = Nil

Past Psychiatric Illness - ? Treatment, ? Admissions.  
 Dementia Yes = 1 No = 0 DEMA \_  
 Other PSYA \_  
 Alcohol abuse ALCO \_

Note details but only score for previous admission or not

Social Situation  
Type of accomodation ACCO \_  
 1 = Own House, 2 = Own Flat, 3 = Rented House, 4 = Rented Flat, 5 = Council House, 6 = Council Flat, 7 = Sheltered Flat, 8 = Residential Care, 9 = Unclassified, 0 = Other.

Condition of home  
 Structural 0 = good, 5 = extremely dilapidated STRU \_  
 Superficial 0 = good, 5 = ext. dirty/neglected SUPE \_

Support Services  
 level of practical support provided by each  
 4 = Full, 3 = Major, 2 = Minor, 1 = Contact only.  
 5 = some support  
 can't rate extent

Home Help	HELP	-
Meals on Wheels	WEAL	-
Day Centre	DAYC	-
Social Worker	SOCW	-
District Nurse	DIST	-
CPN	CPNU	-
Voluntary Worker	VOLW	-
Relatives	RELI	-
Other	OTHR	-



Onset of illness (months and years ago)                    \_ \_ \_ \_ \_  
Date of acute deterioration (in last 6/12)                    \_ \_ \_ \_ \_

Recent deterioration in (in last six months):

3 = Severe, 2 = Moderate, 1 = Mild, 0 = Nil:

Mood - Irritable / Suspicious                    IRSU    \_  
         - Depressed / Withdrawn                DEWI    \_  
  
Behaviour - Restless / Wandering                WAND    \_  
         - Aggressive / Disinhibited              AGDI    \_  
  
Cognition - Memory / Disorientated / Confused    COGN    \_  
Self Care (personal hygiene and appearance)    SELC    \_  
   Sleep Pattern                SLEP    \_  
   Contenance                CONT    \_  
   Other                    OTHE    \_

LIFE EVENTS NOTED IN LETTER (in last six months)

LIFE EVENTS (name of event)	LEDS - ratings		Distress Scalings (not used)
	Threat	Independence	
A.			
B.			
C.			
D.			
E.			
F.			
G.			

How likely do you think it is that the person was admitted as an inpatient or day patient at an old age psychiatry unit as a result of this letter?

1) very, 2) fairly, 3) don't know, 4) fairly unlikely, 5) very unlikely                    \_

If you think the patient may have been admitted (answer 1,2,3 to question above) please list the three most likely factors leading to the decision to admit in order of priority;

1st                    .....  
  
2nd                    .....  
  
3rd                    .....

### **7.3.2 Manual for assessment letter study**

#### **CODING GUIDE: for Data Package - Psychiatric assessment in the elderly:**

**EDUC** Educational level, 1 = Degree or diploma, 2 = Trade training or apprenticeship, 3 = Left school at 14 and Standard 7, 4 = Left school before 14 or less than Standard 7.

**SOCL** Social Class defined by principle occupation before retirement,  
1 = Professional, 2 = Managerial, 3 = Skilled, 4 = Semi-skilled, 5 = Unskilled.  
If married and/or not in full employment define by spouses job.

#### **Physical Illness:**

**Severe** = Possibility of a real threat to life AND/OR resulting in severe disability or discomfort.

**Moderate** = Significant threat to physical well being AND/OR resulting in moderate disability or discomfort.

**Mild** = No significant disability, mild discomfort AND/OR latent physical threat.

#### **Social Situation:**

Support services; level of support provided, is defined according to each specific service i.e. Rating 'full' for RELI (relatives) would mean the subject required close supervision by a cohabitee relative who probably received not much help from other sources. Rating 'full' for a day centre would be an attendance of 5 days per week. On the other hand a community psychiatric nurse (code CPNU) should be rated 'full' for daily visits and assistance, whereas a 'minor rating' would do for visits weekly or less.

**Date of onset of psychiatric symptoms & Date of any recent deterioration (in past six months)** Try to get year and month if possible. If some idea make estimate e.g. if began two years ago date as two years previously for example 24.4.90. If no idea code all as 99s. Do not code as partly 99s - either all or nothing.

#### **Rating of deterioration:**

For ratings of deterioration one needs to take into account the previous level of functioning. For instance, if someone has always tended to be suspicious then a slight



increase in this may only merit a 'mild' rating. A more pronounced increase especially if it affected their behaviour could justify a 'moderate' or even a 'severe' score. On the other hand, a person who was previously not suspicious or irritable but became noticeably so in the course of their deterioration may require a 'severe' rating.

### **RATING OF LIFE EVENTS**

Life events should be coded according to two scales, the Bedford College Life Events and Difficulties (LEDS) method. The key objective is to identify life events and decide if they are mild, moderate or severe.

7.4.0 Follow up study - data sheet

Follow up of first 60 admitted day and in-patients

Patient Number

---

Follow up date

---

Date admitted

---

Date of Birth

---

Age

---

Sex (M=1, F=2)

---

Dates of admissions and discharges (since November 1987)

<u>Admitted</u>	<u>Discharged</u>	<u>Ward</u>	<u>Hospital</u>

Dates in and out of:	<u>In</u>	<u>Out</u>	<u>Where</u> (name)
1. Residential Care	.....	.....	.....
2. Day Care	.....	.....	.....

Current Status

Died?

Date Died

Hospital/

Ward

Residential

Care

Community (Type of

accommodation

)

Physical illnesses (since November 1987)

Date

Illness



### ***7.5.0 Life events in the elderly***

## **International Review of Psychiatry**

**Psychiatry of the Elderly (eds. MW Orrell and CLE Katona)**

**Ageing: Developments in Research and Service Provision  
1994, Volume 6, Number 1, (in press)**

### **Life Events in the Elderly**

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## **Life Events in the Elderly**

Martin W Orrell and Ann D M Davies

**Summary:** The psychological mechanisms for the actions of life events are discussed with respect to how stressful life events may have different impacts depending on the age of the individual. The methodology of life event research in the elderly is reviewed, highlighting the problems of using checklists to elicit events. Lastly, the potential for life events to precipitate or exacerbate psychiatric and physical disorders in the elderly is emphasised.

Research on life events in the elderly presents a complex scenario (Davies, 1993a). It is clear that on a life-time scale, most old people have accrued more 'events' than younger people but what does this signify? One strand of research influential within social psychiatry has viewed life events within a stress paradigm. Life events are stressors which, by requiring adaptation and making demands on resources, cause or trigger psychological distress and onset or relapse of psychiatric illness (Creed, 1993). A review of epidemiological studies by Cooke and Hole (1983) concluded that in about a third of psychiatric cases stressful life events had a causative role and Brown and Harris (1989), in a prospective study in Islington, reported that 37 percent of women who had experienced particularly severe events became depressed. A pioneering study by Murphy (1982) extended stressful life events research to old age. The experience of severe events was found to play an important role in depression in old age, but major chronic health and non health difficulties also had a role. The life stress paradigm poses questions for late life psychiatry. What is the relative impact on mental health of **life events** (discrete occurrences e.g. bereavement) and other stressors such as chronic **difficulties** (e.g financial or family problems) or even **daily hassles** (minor irritating and frustrating occurrences such as having arguments or being kept waiting, Kanner et al., 1981)? What type of older person experiences stressful events? Are there some types of event such as a bereavement or a residential relocation that are of such significance for the older person that a single occurrence is sufficient to trigger an illness onset or relapse? These questions are methodologically important because it is clear that events do not occur randomly in the population and controlled



experiments are not possible. Life events happen to older adults who already have psychological characteristics and distinctive health and social circumstances. It is for this reason that Brown and Harris (1978) have placed so much importance on event definition, 'independence', and contextual threat.

Another research tradition sees most life events as markers of developmental transitions which are normative for the older person, the family and society. Births and deaths, children leaving home, retirement and relocation are to greater or lesser extent markers of underlying developmental processes. Each will have its antecedents, course and outcome. It is artificial to regard such processes as discrete 'events' because although an occurrence can be pinpointed to a given day, the underlying **psychological processes** and pattern of interactions with the world are seamless (Brim and Ryff, 1980). The critical distinctions within this paradigm are whether the 'events' are 'normative' or 'non normative' for the developmental stage. Normative developmental markers are unlikely to be such severe stressors, partly because the transitions are expected and socially condoned, partly because in late life there will be many appropriate role models to help appropriate adjustment. Non normative events however may be rightly regarded as stressors leading to psychological distress, since there are fewer social resources and few role models. Thus depression might be a consequence of a criminal attack or the loss of the home through disaster but would not be so likely to follow the anticipated death of an elderly spouse or sister. The type of event, its developmental and social context, the perceived demand on physical and psychological resources in relation to available perceived resources determine whether or not a given event is or is not a stressor.

### **Mechanisms for the action of life events**

The effects of a life event on the individual depends on a number of factors:

- The degree of threat (Brown and Harris, 1978)
- Any predisposing vulnerability to develop an illness (Brown and Harris, 1978)
- The time at which the effect of the event is measured (Brown and Harris, 1978)
- Whether there are co-occurring chronic problems contributing to raised 'adversity' (Davies et al, 1988)

- How the individual evaluates the meaning of the event (Brewin, 1990)
- the individual's 'hardiness' or resiliency (Wieber and Williams, 1992)
- Coping strategies of the individual (Brewin, 1990)
- Presence or absence of social support (Brewin, 1990)

From the work of George Brown we know that for young subjects type of event can be important: events signalling loss are critical for depressive onset whereas events signalling danger are critical for anxiety (Finlay-Jones and Brown, 1981). There has been little research of this kind with older people, though surveys suggest that older people experience fewer events in total than younger (Masuda and Holmes, 1978; Lazarus and DeLongis, 1984). In particular there are few studies on the relation of type of event to precipitation of specific physical illnesses in late life.

Brown and Harris (1978) suggest that for depression the effects of life events are moderated by self esteem. High self esteem has a protective effect and low self esteem an undermining effect on the subject's capacity to avoid depression when exposed to stressful life events. If this is the case positive events or factors which increase self esteem such as social support should protect against depression or initiate recovery from it (Brown et al., 1992). Self esteem has been found to be protective against depression in older adults (Murrell et al., 1991), and positive events (those that represent an accomplishment) predict positive affect (Murrell et al., 1992). Oatley and Bolton (1985) suggest that life events act by disrupting the roles by which people define their worth, and have their maximum adverse impact if these people lack an alternative source of self-definition. Events also undermine the predictability of the individual's life disrupting plans. This view accords with Neugarten's (1970) developmental conception of the stress of life events. Her view is that we have to consider whether an event is 'on-time' or 'off-time' for the person's stage of development. Rook et al. (1989) developed this notion into a 'social clock' theory that postulated that stress will be experienced when the event is 'off-time' for the life stage. A bereavement will be more stressful if the death is 'off-time' (e.g. occurring unexpectedly in young adulthood) than when it is seen as a normal or expected occurrence in late life. For older people death of an adult child will be particularly



upsetting since it upsets the 'natural order' of events (Goodman et al., 1991). Ehlers et al. (1988) seek to unify the social and biological perspectives by suggesting that psychosocial stresses disrupt the individual's social rhythms or 'zeitgebers' which in turn could result in a disruption of biological rhythms, thereby causing depression. Hofer (1984) has detailed how spousal bereavement may have this effect. Potential biological mechanisms for the action of life events including the effect on the neuroendocrine and immune systems and the possible interactions with genetic factors have been discussed in another chapter in this issue (O'Dwyer and Orrell, 1994).

### **Methodology of life events research**

Creed (1985) mentions three ways to investigate the relationship between stress and illness: studying a population exposed to a specific **stressor** such as bereavement (Parkes et al., 1969) or relocation (Anthony et al., 1987); relating recent life stress to the onset or progression of a specific illness such as depression; and the controlled use of an experimental stressor in a given population. The first method is quasi-experimental in nature, the second is the well known case-control method but the third cannot normally be used on ethical grounds. Controlled experimental studies are therefore lacking: we do not normally know what the individuals experiencing the stressors were like **before** the life event. Prospective follow up studies of populations overcome this objection. This strategy has emerged as a by product of longitudinal research into ageing. An ongoing study of subjects whose health characteristics, social support and personality type are measured is followed up over a number of years. The progress of those who later experience the events of interest can be examined, taking into account their pre event health and personality. The impact of event type, severity and frequency, can be studied as can the question of **what type of person** experiences a given event (event occurrence vulnerability). Clearly we cannot assume that events are distributed randomly in the population and the observed relationships between life events on conditions such as depression are conceivably not to the events as such but rather to pre-existing personality and coping characteristics. It was for this reason the Brown and Harris (1978) paid such attention to rated 'independence' of events from psychiatric illness. The prospective panel study however allows the **empirical**

examination of the role of pre-event characteristics on psychological distress post event.

Before one can conclude that life events cause psychiatric disorder studies must fulfil certain criteria (Cooke, 1986; Maes et al., 1987).

- Clear statistical association between life events and psychiatric disorder
- Evidence that life events lead to illness not vice versa
- Satisfactory theoretical explanation for life events specifically leading to disorder (taking into account effect of possible confounding variables).
- Association between life events and illness replicable across different populations and times.

Most large scale community studies of life events have used a check list approach. Dohrenwend et al. (1987) found the great majority did not meet minimal criteria of methodological adequacy. This is primarily because studies used inappropriate controls, had problems dating events in relation to episodes of illness and did not take into account whether events occurred independently of the subject's prior mental state and behaviour. As Creed (1993) has pointed out the checklists often have ambiguous questions which leave the subject to decide what to judge to be a 'serious illness' or a 'family member'. Some of the 'events' can themselves be construed as symptoms e.g. change in eating or sleeping habits. Since there is no attempt to prompt recall (or check accuracy of replies) questionnaires may miss as many as 36% of life events (Klein and Rubovits, 1987) Inter-informant reliabilities can be as low as 22% (Neugebauer, 1983). Their use for research with the elderly is further limited by the fact that there is a heavy weighting of items normative for young adults (starting work, having a baby). It is therefore not surprising that Holmes and Masuda (1974) report that subjects in their twenties report twice as many events as those over 60. A further problem with the checklists is that they confound acute stressors, with chronic ongoing difficulties. Items such as 'trouble with in-laws' operate over a different time scale from 'change in residence'. Although it can be argued that many acute events are in fact better construed as longer term evolving changes, the checklists do not allow us to separate the 'one-off' from the continuing stressor. There are however a number



of life events checklists devised for or modified for research with older people. They are reviewed by Chiriboga (1989).

The main alternative to the checklist method is the Bedford College Life Events and Difficulties Schedule (LEDS) of Brown and Harris (1978). The LEDS makes a number of advances in eliciting, recording, and accurately dating life events. An independent 'panel of raters' scales the degree of 'threat' to the subject in the light of contextual information but without knowledge of the subject's emotional reaction to the event. Following work of Brown and Birley (1968) the 'independence' of the event from possible psychiatric contaminating factors is also rated. The 'panel' method therefore enables an objective measure of threat to be made without either bias in reporting from the subject, or interviewer expectation bias. The panel can also be kept 'blind' as to whether or not the subject is from a patient or control groups, though the nature of the events reported may allow raters who know the research literature to make informed guesses. Intra informant agreement on event occurrence is around 80 percent. Even raters with inky brief training can reach acceptable reliability for rating Brown and Harris's contextual measure of threat (Tennant et al., 1979). The LEDS interview method has been found to be suited for research with older people and its reliability is as good with this age group as with younger samples (Wilkinson et al., 1986).

Early research on life events hypothesised that events were stressful because they reflected 'changefulness' the need for social readjustment. This was superseded by the 'threat' concept (Brown and Harris, 1978) because positive events had little explanatory power in predicting adversity or psychiatric or physical morbidity (Bebbington, 1987). The two measures are not mutually exclusive however. This may be of particular importance in certain populations (such as dementia sufferers), where the individuals are known to be especially sensitive to routine or environment changes. Rating changes in routine and environment would also allow evaluation of the theory that life events act by causing disruption of social rhythms (Ehlers et al; 1988). Orrell et al., (1990) have shown that changes in the routine and environment brought about by a life event can be reliably rated after a brief period of training. It is quite possible

that the effects of "threat" are to some degree independent of the effects of changes in routine or environment and further research is needed.

### **Life event research methodology in the elderly**

There has been less research on the effects of life events on older adults than on the young though there are reasons to think that there may be important age differences. Older people have fewer physical reserves and a more fragile homeostatic balance, so might be thought to be at particular risk for the adverse effects of events, especially those that are **non normative** (e.g. natural disasters). On the other hand today's elderly are an elite of those who have survived adaptive demands in the past and their greater experiences of stress may have made them generally resilient (McCrae and Costa, 1988). Part of this resilience may lie in the adoption of a philosophical stance of stoicism whereby loss events are regarded as to be expected (Neugarten, 1970). Additionally experience may provide specific competencies. Norris and Murrell (1988) interviewed older adults after severe flooding and found that who had previous experience of floods showed less anxiety and distress. From the developmental perspective the experience of life events in late life is seen as part of adjustment to ageing. Coping strategies, attributions, social support and personality factors, far from being contaminating factors, are of the essence.

Most of the life events on events checklists are **normative life transitions**. Reaction to an event will depend in part on whether there are available role models. Thus elderly women might be expected to suffer less from spousal bereavement than younger women or than elderly men because in our society, where women marry men older than them, widowhood is a more expected state for the older woman and there are many role models (Wortman and Silver (1990). Reaction to an event will also depend on how one has responded to events at earlier periods in life and whether the previous developmental 'tasks' have been accomplished.

Within an older population however, there may be subgroups whose resources are already stretched by reason of chronic 'difficulties' such as poverty, or housing problems. These people would be expected to be most at risk for the adverse effects



of events, particularly if there is a vulnerability which predisposes to a specific illness; a history of maladaptive coping or lack of social support.

Most of the models of possible psychosocial mechanisms for the action of life events, have used depression as the outcome variable. Life events appear to have a role however, in precipitating many other physical and psychosocial disorders, although the range of applicability of the stress-illness model is largely unexplored to date. Most of the studies have been on non elderly individuals and even for depression, where there have been key studies (e.g. Murphy, 1982) there are real questions about the generalisability to older adults of a model developed for younger samples. Depression may present rather differently in old age, with more somatic and fewer affective components than in the young (Berry et al., 1984).

#### **How older adults view life events**

The life span developmental view that the impact of an event is dependent on its timing in relation to other events, to the person's appraisal of it and to the person's stage in the life cycle could raise problems for the development of an objective metric of threat. The LEDS methodology requires a panel of raters to rate the threat experienced by subjects. Where the panel is substantially younger than the elderly people being studied, they may be influenced by their own stereotypes of what it is like to be old. Yet we know that sometimes older and younger adults perceive the same events differently. Hughes et al (1988) found that retirement was seen more positively by older people than by the young. More generally, Ferraro (1992) found that younger people tended to regard older people as more needy and disadvantaged than the old themselves. This has been named 'compassionate stereotyping'. The direction of error might be to see events as being more 'threatening' to older adults than they actually are. This bias would in turn lead one to conclude that in older samples life events had less power to precipitate illness than in younger groups.

A number of studies have examined the reliability and validity of the LEDS procedures used with the elderly with this point in mind. Fortunately trained raters can attain high levels of reliability in rating events and difficulties from interviews with older adults and they can train previously inexperienced raters to their standard

(Wilkinson et al., 1986). Do old raters differ from young however when they rate events occurring to the elderly? In a cross sectional study of women raters no significant age differences were found in rating events drawn from LEDS interviews with older adults, except that older women raters perceived death events as less threatening than did younger women (Davies and Hulligan, 1985). Wilkinson et al. (1985) also examined subjects' perception of chronic difficulties as well as events. There were no significant age differences in perception of the threat of events of any type. Davies et al. (1987) also found no significant differences in between older and younger subjects, the ratings of threat by both groups agreed closely with the ratings of a trained panel whether or not contextual detail was supplied. Finally a study by Ann Davies and her colleagues (1993) (unpublished) looked at the training of a panel of older adults in the LEDS rating panel techniques. There was close agreement between the older panel and a younger professional panel for most events but once again the older panel rated deaths as being less threatening. This series of studies suggests that the LEDS is reliable and robust, but there is some evidence that a rater's stage in the life cycle does have some influence on the severity of threat at least for deaths. We do not know whether older raters judging events they themselves have experienced would report lower stress but it is reasonable to suppose so, since in the study discussed the raters had all had experience of deaths of close family or friends. One panel member reported that his grief at the death of his adult daughter far surpassed his grief at the death of his wife. His experience fits the 'on time'/off time' distinction made by Neugarten (1970).

Since in the elderly population some people may have memory or other cognitive difficulties some studies have looked at the life events rating by informants to assess the reliability of life events reporting. There is high reliability between elderly subjects recall of severe events and those of relatives (Murphy, 1982).

### **Frequency and type of life events in the elderly**

Studies using event checklists find that older people report fewer events overall than younger people, though this may be due in part to the inclusion of items not relevant to the elderly. Cross sectional studies show that older adults report more loss events



such as deaths and declines in health. (Masuda and Holmes, 1978; Lazarus and DeLongis, 1984; Hughes et al., 1988). French et al., (1992) however note the difficulty of interpreting health items. They point out that *'health problems may lead to objective undesirable events or reduce the potential for objective desirable events'*. This may be a problem in the elderly because of the relatively high rate of physical illness. Murrell et al. (1984) found that half of his community sample had experienced a health event involving hospitalisation, either for themselves or for a family member. Davies (1993b) in a British rural sample also found that health events and difficulties the most prevalent components of 'adversity' in a study using the LEDS procedures (Davies et al., 1989). Even with the LEDS method, health events cannot be construed as truly 'independent' events for someone whose health status is already poor: the problem remains that maybe we are just showing that prior ill health predicts subsequent ill health.

In addition to finding the expected reduction in reporting in an older group, Oei and Zwart (1990) found that a depressed group reported more events than the non-depressed. Horowitz et al. (1977) found an age difference in the way subjects judged the impact of events over time intervals ranging from one month to three years. Subjects under 30 rated events as more stressful during the first month but their impact dissipated quickly over time. Those over 30 however saw time as less healing. The cross over point was at 6 month after the event.

Murrell and his co-workers have carried out an extensive series of studies with older adults looking at the way positive and negative impact on a population. Over a one year period positive events were more frequent. Additionally, some events though highly undesirable had low population impact because they were rare (e.g. death of a spouse, retirement) (Murrell et al., 1984). Many of the 'events' e.g. 'visit to a museum', 'trip out of town' would not qualify for rating on the LEDS scale. Although the research on population impact is important for better understanding of the context of events, it is worth noting that one might expect the **personal impact** of events to be inversely related to the **population impact**, because in developmental terms it is the **non normative** nature of events that makes them stressful. Positive

events have been related to happiness by Murrell et al., (1992) who found that they also had interactions with some types of social support. A measure of **functional support** (how much help one could anticipate if it were needed) was related to positive affect on the Bradburn scale and a well being measure but was not related to the occurrence of events. However **structural social support** (availability) was related to the occurrence of positive events. Older people may need to be able to key into social network structures to be able to take advantage of potential positive events such as trips or events that allow them to demonstrate accomplishments. Such findings are useful in planning strategies to prevent depression.

## **Life events and psychiatric illness in the elderly**

### **Depression**

Many studies of the effect of life events and depression in the elderly are not easy to interpret, since definitions of 'depression' differ. Some studies (e.g. Murphy, 1982) measure depression by clinical diagnosis, others (e.g. Davies, 1993a) by standardised diagnostic criteria, yet others use self report measures of depressed mood (Linn et al., 1980). These differences in definition of outcome criteria may be important. Additionally, whilst some studies use the checklist or interview methods already discussed, others confine themselves to single events such as bereavement, which are assumed to be stressful by definition, rather than being considered within the context of their **meaning** to the individual.

### **Studies using the LEDS**

Using the LEDS, Murphy (1982) compared 168 community controls selected from local general practices, with 119 patients who had experienced an episode of depression in the previous year. The results suggested an association between severely threatening life events, major social difficulties, poor physical health and the onset of depression. The higher incidence of depression in working class subjects appeared to be related to their poorer physical health and greater social difficulties. Murphy suggested that lack of a confiding relationship was a 'vulnerability factor' which made people exposed to life events more susceptible to developing a depressive episode. However, analysis was univariate rather than multivariate and it is hard to estimate the



relative contribution of the various factors. In a follow-up study (Murphy, 1983) showed that severe life events after onset contributed to a poorer prognosis but a confiding relationship did not appear as protective factor. Baldwin (1991) has suggested that the poor prognosis could be associated with the relatively low usage of ECT treatment for the patient subgroup with more biological and psychotic symptoms.

Since Murphy, several other studies have used the LEDS to examine the role of severe threatening life events in onset of depression (Lam et al., 1987; Burvill et al., 1991; Evans and Katona, 1993; Davies, 1993a). Lam et al., (1987) were primarily interested in negative cognitive patterns of a group of hospital in- and out-patients who met RDC criteria for depression and a group of controls. Patients experienced more severe threat events in the year prior to the interview than controls (52% versus 26%) but there was no significant difference in difficulties (39% v 26%). When the subjects were divided into those who had or had not experienced some form of adversity (event and/or difficulty) it was found that adversity was not related to negative cognitions. Lam et al., caution that presence of difficulties or events should not be regarded as sufficient explanation for negative cognitions. The depressed group had negative cognitions whether or not they had experienced events or difficulties, suggesting that events may be a weaker influence in the aetiology of depression in the elderly.

Davies (1993a) reported the results of a community sample of elderly people and a further sample of hospital inpatients. There was a significant effect of both life events and difficulties on DSM III depressive symptoms. As chronic difficulties seemed to exert more of an effect on depression than events, a composite measure of adversity was derived, in which each subject's total array of events and difficulties were judged by an using the LEDS independent panel method (Davies et al., 1989). Adversity was found to be significantly related to the number of DSM III depressive symptoms and a log linear analysis showed that social support exerted a directly protective effect against depression. In both the Murphy and Davies et al. studies, health difficulties played a significant role in depression in the elderly. Davies (1993a) also reported that difficulties were far more prevalent than events. However, Burvill et al., (1991) in a prospective study of patients over 12 months however found neither chronic health

problems nor occurrence of a severe event significantly influenced prognosis in an already depressed old sample.

In conclusion, the few studies using the LEDS method with older people suggest that depressed elderly people do have more events than the non depressed but negative cognition, chronic health problems, and lack of social support may be influential in determining whether or not an individual goes on to develop a depressive illness. Older people who have negative cognitions seem to be at risk of depression, with or without events.

### **Studies using checklists**

The checklist method lends itself to large scale studies which allow the testing of specific multivariate causal models incorporating such factors as initial levels of depression, initial social support, hassles, and events. In a study of 188 community elderly Linn et al. (1980), using a version of Rahe's Recent Life Changes Questionnaire, examined the relationship between depression and certain life events in the previous year. They found that depressed subjects had experienced more arguments with friends and (once marital status and disability were partialled out) had experienced more deaths of friends. The number of events experienced was however was small (1.6 for depressed and 0.9 for controls) and there were no significant differences for events such as illnesses or financial problems. Smallegan (1989) attempted to replicate this study but noted that her sample had more events yet less depression than in the Linn et al., study. There was no overall significant relationship between events and depression and no evidence of a cumulative effect of events on depression. In neither of these studies could the samples be regarded as having levels of depression comparable to a psychiatric diagnosis of depressive illness.

Patrick and Moore (1986) looked at life events and attributional styles as predictors of depression in elderly women by using the Geriatric Schedule of Recent Life Events (GSRE). The study found that the undesirable life events which the subject felt helpless to control were significantly related to depression. Although Patrick and Moore did not use an independent assessment of the controllability or 'independence'



of life events (which would have been less susceptible to subject bias), they do give us an idea that the subject's own perception of the controllability of the life event may be important.

Cutrona et al., (1986) found that neither negative events (measured by a version of the Social Readjustment scale adapted for the elderly) nor social support were related to mental health measures including the Zung self report depression scale but depression was predicted by their interaction i.e. once events had occurred older people who had higher social support had a better outcome. In contrast, social support, but not event occurrence predicted physical health outcomes directly. Russell and Cutrona (1991) went on to test a model of social support, events, and depression in which initial depression and initial social support were hypothesised to lead to subsequent life events, which in turn could lead to hassles. Over an 18 month period major events and hassles were measured monthly. The Zung scale was again the outcome measure. Causal modelling showed general support of the model and there was a weak relationship between initial depressed mood and occurrence of major life events: depressed subjects were at risk of more events and also hassles, which increased the risk of their remaining depressed over time. No buffering effect of social support was found but once again, this study was carried out with people with levels of symptomatology much lower than would be found in psychiatric practice.

Hurwicz et al., (1992) asked respondents to generate their own lists of events, changes that had the most impact on them during the last 12 years (the period of a longitudinal study). Not only did older people list fewer events but there was no relationship between events and depression for the grandparent generation of the three generation families studied. This finding is perhaps unexpected, since one could have expected the subjective appraisal of impact to have maximised an association with depression. Possibly this methodological factor is less important in older groups than in the younger. Nacost and Wise (1991) also using a three generation design, examined the relationship between negative events and two cognitive attributes thought to mediate the relation between events and depression: dysfunctional attitudes and negative automatic thoughts. Although both events and automatic thoughts predicted Beck

Depression scores in the oldest group they did not interact: negative thought exerted an effect irrespective of whether there was exposure to events or not. This replicates the Lam et al (1987) study discussed above. Stable dysfunctional attitudes did not play a role in the depression of old age, which led the authors to suggest that depressed mood in late life is more transient. Davies and Gledhill (1983) also noted the increased lability of depressed mood in the elderly.

### **Depression and specified event types**

Of all the life events thought to trigger depression, spousal bereavement has been the most studied and since this event type would normally be considered to be severely threatening by panels trained in the LEDS methods, investigations of the impact of bereavement afford a certain degree of comparability across methodologies. Grief experience of older widows appears to be milder but more long lasting than that of younger widows (Atchley, 1975; Heyman and Gianturco, 1973; Sanders, 1980). But bereavement may be anticipated or unexpected; it frequently has consequences for the financial situation and housing of the survivor and it may also follow a partnership of short or long duration standing, which has been more or less satisfactory. All of these factors might influence outcome. The implications of bereavement for an elderly person with grown children differ from those of the young widows. It is important to note that death of a spouse is not only an event in its own right but also removes an important component from the survivor's social support network, and it may be this depletion rather than the grief per se that is associated with poor outcome. Widowhood is also a social status: being single may have an enduring effect if the social circle is geared towards couples. Thus the impact of spousal bereavement is multi factorial: a composite of event, ongoing difficulties, hassles and also pre-existing risk factors for depression such as personality, attributional and coping style.

Norris and Murrell (1990) review literature which suggests that 17-26% of bereaved people are still depressed one year after the death. As part of an ongoing study they identified people who had lost a spouse, child or parent and compared them with non bereaved controls. The design of the study allowed pre bereavement health and depression to be taken into consideration. There were few health consequences of



bereavement, a finding in accord with other longitudinal studies, but depression in their widowed sample rose sharply after the bereavement. A multiple regression analysis showed that at nine months **post bereavement depression** was associated with **prior depression**, higher 'global stress' and lower social support. For those who had lost a child or parent, prior depression was the best predictor of post bereavement depression.

### **Moderating variables**

Of the various possibilities moderators, most attention has been paid to social support and coping, self esteem and physical health and also the occurrence of positive events. The relationships can be complex. Not only does social support moderate the effect of an event such as bereavement but a stressful event itself has an effect upon support available (Krause, and Jay, 1991). The nature and direction of the support may be dependent on the nature of the event. Thus bereavements tend to elicit support from family and friends but financial events have the opposite effect: people receive less help from their social network. Additionally family and friends may fulfil different support needs. Recent studies have tended to disaggregate types of social support including the social contacts, perceptions of support availability, satisfaction with support and anticipation of support in the future. Krause et al. (1990) in a sample of over 1504 British over 60s found that **contact** with family and friends increases the **amount of support received** and was associated with reduced distress measured by the General Health Questionnaire. Social support has been linked to other variables that might be expected to relate to well being, such as adequacy of diet. Those who suffer stressful events are more likely to have an inadequate diet, but this is mitigated by social support (McIntosh et al., 1989).

In all these paradigms is difficult to tell which variable, is causal. Brennan and Moos (1990) for instance found that late life problem drinkers experienced more negative life events and ongoing difficulties than non problem drinkers and had fewer social resources. In a multivariate study, however it was **chronic stressors and social resources** that best explained depression and drinking behaviour, rather than negative life events and other demographic variables.

Coping efficacy has been identified by Zautro and Wrabetz (1991) as a factor that can reduce distress in the face of bereavement or disability. Once again however the situation is complex. Coping success with loss events (e.g. bereavement) was associated with less distress but there was no simple relationship for health events. There are sometimes difficulties in specifying coping efficacy in a non circular manner. 'Successful' coping can be regarded either as a process or an outcome and the concept of 'success' may itself incorporate elements of reduced distress. The concept of self esteem or self efficacy encapsulates an expectation of present and future coping capability. The fact that positive events especially those which give rise to a sense of achievement also have a direct effect on positive affect may also be linked to self esteem Murrell et al. (1991).

Murrell et al., (1991) investigated four possible models of the way self esteem and good health could exercise a protective functioning against depression measured by the CES-D. In particular they were interested in whether resources had to match the characteristics of the stressful event to be protective or whether resources exercised a general positive effect. Their results showed that both self esteem and good health had direct protective effects. The occurrence of the events themselves did not lead to greater depression. Both the resources were negatively related to depression independent of events. Murrell et al., conclude that for older adults the adverse consequences of events may lie not in their stressfulness as such: life events may not be very stressful to older people, but there are indirect adverse consequences through their effect on resources such as health and self esteem.

### **Senile dementia**

A recent case-controlled prospective study, looked at the effect of an enforced move on dementia sufferers (Anthony et al., 1987) as a result of the closure of a large psychiatric hospital and the relocation of the patients to smaller units in two general hospitals. A large proportion of the sample showed significant depressive behaviour following transfer and a significant degree of disturbed behaviour and disorientation remained 3 months after the move. This time lag suggests that the effects of relocation may be relatively long lasting. Harwood and Ebrahim (1992) found no deterioration



in cognitive function amongst 101 elderly continuing care patients who were relocated from one hospital which closed to refurbished accommodation at another hospital and even noted a slight improvement in levels of dependency after the move. However, the patients were not necessarily suffering from senile dementia and the results did not examine whether or not patients who were more cognitively impaired responded more poorly to the move (as would be expected) because of the lesser capacity to adapt to a changing environment. Pruchno and Resch (1988) found that those patients with moderate cognitive impairment and disability were most adversely affected by relocation. Both Anthony et al.'s and Harwood and Ebrahim's studies showed non-significant increases in mortality after relocation, but an earlier study (Crank and Zweig, 1980) showed a significant increase in mortality amongst dementia patients after relocation following a hospital closure.

Studies of relocation with dementing patients have generally involved a move to a more suitable and comfortable environment, usually specifically refurbished with the needs of the frail elderly in mind, and offering better facilities with more single rooms. The hospitals which the patients came from have tended to be old and in the process of closure (Anthony et al., 1987; Harwood and Ebrahim, 1992). For these reasons, the move could be seen as a positive rather than a negative event. In spite of this, the studies so far indicate that relocation for dementia sufferers may lead to depressive symptoms, disturbed behaviour and disorientation, which can persist for several months.

Pitt (1993) states that there is little convincing evidence that stressful life events are significant factors in the genesis of dementia. However, there have been few studies which have looked at the relationship between life events and dementia and none have had adequate methodology. In a study of 25 female elderly patients with dementia compared with 25 fit controls Amster and Krauss (1974) using the GRSE found double the number of life crises in the previous five years. They were cautious in interpreting the results pointing out that cognitive decline could have begun prior to the illness being noticed by relatives and friends. Because of this, early symptoms of the illness could have precipitated more life crises in the dementia group. Also as

Gilhooly (1984) has noted, impairments in coping ability in the dementia patients could mean that they do not deal effectively with stressful events when they first occur which leads to exacerbation of the event or to further events.

In the EURODEM meta-analyses study of risk factors in Alzheimer's disease Jorm et al. (1991) concluded that there was no evidence from case control studies to suggest that life events were a significant risk factor and that further research would be unlikely to be fruitful. However, the meta-analysis only looked at specific life events (death of spouse, death of child and divorce) and several of the papers cited do not mention life events (Broe et al., 1990; Hofman et al., 1989); use their own checklist (Amaducci et al., 1986); or use arbitrary categories such as '5 or more grief causing life events' (Chandra et al., 1987). Jorm et al. (1991) included studies not mentioning life events but merely deduced 'death of spouse' and 'divorce' from marital status. The methods of collecting life events information used in the studies which comprised the meta-analysis are more primitive than the methodology used in the first significant life events research (Holmes and Rahe, 1967). It is unreasonable to accept Jorm et al.'s conclusions since hypotheses about life events and dementia can only be properly tested using adequate methodology. A recent study using the LEDS interview (with informants) looks at the relationship between life events and senile dementia. It compares 50 subjects in a fit elderly community control group with a group of 50 dementia sufferers in the community and a group of 70 dementia sufferers who had recently been admitted to psychiatric units and looks at life events in the previous six months, and three months before an identified deterioration date (Orrell, 1994).

### **Life events and physical illness**

Life events have been frequently linked with the decline in physical health or the subsequent death of the elderly (Rowland, 1977) indicating that their effect is not solely psychological. Parkes et al. (1969) demonstrated that in the six months following bereavement in widowers over 55, mortality was raised by 40%, the commonest causes of death being complications of atherosclerosis, such as myocardial infarction. In a study of 91 men admitted to a coronary care unit following myocardial infarction, Connolly (1976) using the LEDS, found an increased number of



independent threatening life events in the preceding 12 weeks when compared with a matched control group. In a five centre trial using the checklist approach Vogt et al. (1988) studied 551 patients with isolated systolic hypertension and found no relationship between life events and blood pressure.

In 1954 Ecker reported research suggesting that emotional stress and threatening events preceded stroke it was not until recently that the first proper case control study using the LEDS was published (House et al., 1990). Comparing life events and difficulties in 113 stroke patients with a group of 109 age/sex matched controls, House et al. found that the stroke patients were significantly more likely to have experienced a severely threatening life event in the year before stroke onset. Recognised risk factors for stroke were equally loaded in patients with and without life events before onset. The authors noted that there was usually a lag period between the stressful experience and stroke. This suggests that the effects of the stressor may take time to act fully. Because of the association of life events with stroke and with cardiovascular disease life events potentially have a role in vascular dementia.

## **Conclusion**

Studies of life events in the elderly indicate that the Bedford College Life Events and Difficulties Schedule remains the most valid and reliable instrument to use but to date it has been mainly used with relatively simple case-control designs. More sophisticated causal modelling requires larger samples. Large scale studies have either used checklists or, more recently, have concentrated on the process of adjustment and the outcome of experiencing a known severely threatening event such as bereavement.

Stressful life events appear to be have an aetiological factor for psychiatric and physical disorders in the elderly particularly for depression, cardiovascular disorders and death. Studies of other disorders in the elderly have been very limited but Norris and Murrell (1990) suggest that depression is the main health outcome of an event such as bereavement. Social support and positive life events may be protective in depressive illness and could potentially aid recovery.

Several of the studies reviewed in this paper suggest that for older adults events may have less of an impact than chronic difficulties, especially health difficulties. The terms 'adversity' and 'global stress' have also been used to describe the ongoing chronic problems that are found to be associated with depression. Housing and financial problems may have a lesser role to play than researchers have expected, although financial stress can reduce social support.

Recent trends are towards a more complex conceptualisation of the pattern of a life's stresses within a developmental framework : a person interacts with the world continuously and both influences and is influenced by it. Personal characteristics can precipitate events both negative and positive; people can seek out social contact and hence increase the chances of social support availability. An individual can hence engineer the positive events that boost psychological well being and increase self esteem. Disablement brings about many further negative health events, it can remove the opportunities to practice skills and may reduce social contacts in a spiralling fashion. By contrast bereavement in late life is characterised by recovery from depression. Older adults do not seem to consider death to be as threatening an event as younger people do and this supports the 'social clock' theory of events. The older person emerges as someone who may be resilient, in the sense of being able to activate both internal and external reserves.

The reaction of the cognitively impaired older person to events may however be different, since resilience, coping and cognitive adaptation are likely to be eroded by the reduction in cognitive resources. Whilst the extent to which dementing older people are affected by events is still under debate but it seems likely that their chronic reduction in psychological resources makes them more vulnerable to depression and other adverse outcomes.

Life events research has proved more complex than was once thought. It is clear however that being aware of the risk factors for depression **after** an event has occurred (chronic difficulties, previous depressive episode, poor social support etc) can help concentrate mental health resources where they are most needed.



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### ***7.5.1 Stress, ageing and dementia***

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### **STRESS, AGING AND DEMENTIA**

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## **STRESS, AGING AND DEMENTIA**

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### **Summary**

It is well established that stress causes neuroendocrine changes. In particular, the central role of the hypothalamic-pituitary-adrenal axis in the stress response, and the multiple effects of adrenal steroids on neuronal activity, structure and chemistry suggests that the hypothalamic-pituitary-adrenal axis may form a link between environmental stress and psychiatric disease. We review the evidence for a theoretical relationship suggesting that through abnormalities of the Hypothalamic-Pituitary-Adrenal axis, potential mechanisms exist whereby stress and ageing may contribute to neuronal damage and dementia.

Many psychosocial factors play an important role in the course of the dementia (Shan Wang, 1977). These factors may aggravate behavioral manifestations of intellectual decline and undermine physical health. The interaction between these factors may in turn lead to further decline. Shan Wang proposes a 'Sociopsychosomatic' model for dementia and proposes that since little can be done about brain tissue which has lost its functional capacity, the interplay between somatic, psychological and social factors, often becomes the most important determinant of the course and outcome in patients with dementia.

Studies of dementia have usually only looked at stress insofar as it affects the carer rather than the dementia sufferer. However, there is good evidence to suggest that if anything the cognitively impaired elderly are more sensitive to stressful life changes. Symptoms of delirium can be particularly affected by psychosocial factors and alterations in the environment (Lipowski, 1992) and for dementia sufferers changes in environment or routine can cause distress and cognitive deterioration which may be persistent for several months (Anthony et al., 1987). From the psychosocial perspective life stress can cause major emotional changes (such as grief reaction as a result of loss), which may be more difficult to cope with or resolve for someone with cognitive impairment. The mood



disturbance, particularly with agitation and anxiety, could in turn impair performance and exacerbate confusion or could draw attention to someone with an existing dementia. Individuals with dementia are more sensitive to loss of role and a stressful changing or unpredictable environment because their cognitive impairment impairs their ability to adapt to new or stressful situations. Verwoedt (1976) suggests that severe psychological upsets can cause brain decompensation and that a *'progressive accumulation of disturbing emotions ..... may produce a neuronal turmoil which reduces the homeostatic and information processing capacity of the brain. When the status of the brain is already borderline, any further decrease of its efficiency is enough to tip the brain into decompensation'*.

### **Stress and aetiological factors in dementia**

Apart from the well established finding that Alzheimer's disease (AD) increases with age (Wilcock and Jacoby, 1991) and may be slightly increased in females (Amaducci and Lippi, 1992) the search for causative factors which could account for the majority of cases has been less promising. Great advances have been made in understanding the genetics of the disorder but although this may provide an explanation for many cases occurring below the age of 65, so far genetics appear unable to account for the great majority of cases which appear to be sporadic in origin with perhaps only 20% having had a family history of AD. Past history of depression and immunological changes have both been considered as possible aetiological factors for Alzheimer's disease, and this is relevant since both the depressive and immune changes can also be precipitated by stress.

Although Pitt (1992) in his review concludes that there is little convincing evidence that depression is a risk factor in the genesis of dementia there have recently been several case-control studies with adequate methodology which suggest that a previous history of depression may predisposed to later development of Alzheimer's disease (Amaducci and Lippi, 1992). Amaducci and Lippi (1992) pointed out the difficulties of research in this area because the diagnostic clinical criteria for AD (McKhann et al., 1984) used in many studies could make it difficult to study previous psychiatric disorders. However, three

case control studies (Shalat et al., 1987, Broe et al., 1990; French et al., 1990) found that a previous history of episodes depression was significantly more frequent in AD cases compared to controls. Moreover, the re-analysis of case-control studies by the EURODEM Risk Factors Research Group found an association with a history of depression in late-onset cases of AD (Jorm et al., 1991).

Immune mechanisms decline with ageing, and it has been suggested that AD could be an acceleration of that process (Nandy, 1978). Amyloid is believed to be deposited in the tissues under conditions of altered immunity and high levels of IgG have been noted in the amyloid fibrils in the plaques (Ishii and Haga, 1976). Significant correlations between tests of cognitive function and levels of serum immunoglobulin were found in a comparison between inpatients with AD and age-matched controls (Eisdorfer et al., 1980; Cohen and Eisdorfer, 1980). Heston et al. (1981) showed an increased incidence of immune-system disorders in the relatives of patients with Alzheimers disease, but in a review Henschke (1987) concluded that despite the advances in immunological research methods, no worthwhile clue to any immune mechanism of pathogenesis currently exists in Alzheimer's disease.

#### **Areas of neuronal damage in Alzheimer's disease**

In Alzheimer's disease, and vascular dementia, memory deficits are characteristic clinical symptoms which occur early in the disease process (Wilcock and Jacoby, 1991). The hippocampus is a key area for memory storage and processing and is also one of the principle areas affected by the pathological changes of Alzheimer's disease (Esiri, 1991). The hippocampus is also a principal component of the HPA axis (Sapolsky et al., 1986a). As part of the limbic system, the hippocampus has a role in the manner in which psychological stressors affect function of the HPA axis and control of the 'stress' hormones (Pert et al., 1989). Another important area of neuron cell death in Alzheimer's disease is the locus coeruleus (Roth, 1986) which has important noradrenergic projections to the hippocampus (O'Keefe and Nadel, 1978). The locus coeruleus has many glucocorticoid receptors which act as a part of the negative feedback system regulating



the HPA axis through hippocampal noradrenergic projections to help control cortisol levels (Yehuda et al., 1990).

### **Regulation of the Hypothalamo-Pituitary-Adrenal Axis**

The secretion of glucocorticoids by the adrenal cortex in response to a variety of stressors is the final stage in a neuroendocrine cascade which begins with the perception of a stressor and the triggering of hypothalamic release of Corticotrophin Releasing Factor (CRF) (Vale et al., 1983). Other agents may also mediate this response, notably Vasopressin (Arimura et al., 1969), and, in foetal and neoplastic tissue, catecholamines and Vasoactive Intestinal Peptide (Jones et al., 1988). This stimulates the release of ACTH from the pituitary which in turn stimulates glucocorticoid release from the adrenal glands. Glucocorticoids act on receptors in the brain and pituitary to regulate the axis by inhibiting CRF and ACTH release (Keller-Wood and Dallman, 1984). In this way the axis forms a closed loop feedback system (Sapolsky et al., 1986a).

Evidence for the involvement of the hippocampus in the regulation of the HPA stems from a variety of sources. The hippocampus, as part of the limbic system, was noted to have a role in the effect of psychological stressors on HPA function (Mason et al., 1961). Lesions of the hippocampus tend to cause glucocorticoid hypersecretion both basally and in response to stress (Jacobson and Sapolsky, 1991). Hippocampal stimulation inhibits the axis (Dunn and Orr, 1984). A further body of evidence implicating the hippocampus in HPA axis regulation has been the demonstration of adrenal steroid receptors in the hippocampal formation (McEwen et al., 1968). Two types of corticosteroid receptors have been demonstrated in brain tissue. The Type I receptor is almost exclusively septohippocampal in distribution and binds with high affinity both naturally occurring glucocorticoids and mineralocorticoids. The Type II receptors are distributed throughout the brain and are particularly found in association with neurones playing a role in the stress response (Reul et al., 1986). The presence of both Type I and Type II receptors in the hippocampus distinguishes it from most potential feedback sites, as they allow control of HPA function over a wide range of corticosteroid concentrations (Sapolsky et al.,

1986a). Overall, the hippocampus appears to exert a predominantly inhibitory influence on basal secretion (and possibly circadian rhythm of the HPA) and also helps in terminating the adrenocortical stress response (Sapolsky and Plotsky, 1990). This role appears to be a manifestation of glucocorticoid negative feedback inhibition (Fischette et al., 1980). It must be noted however, that the inhibitory strength of the hippocampus has circadian fluctuation and shows a degree of redundancy in regulation as there is potential for recovery of function with time following hippocampal damage (Meaney et al., 1988). Nonetheless, the hippocampus is of particular interest as it appears to be the most vulnerable site to damage, particularly relevant in the setting of hypercortisolism as we shall discuss later.

### **Stress and HPA axis function**

The relationship between life events and hypercortisolism in depression has been explored in a number of studies. Three studies (Roy et al., 1986; Zimmerman et al., 1986; Roy, 1988) found a lower rate of undesirable life events in the DST non-suppressors. However, only one of these studies looked at independent and non-independent life events (Zimmerman et al., 1986) and only non-independent life events were fewer in the non-suppressors. This suggests that the excess of life events in the depressives with normal cortisol control might be accounted for by life events which they themselves had precipitated. Sashidharan et al., (1984) using the LEDS interview found a higher rate of severely threatening life events in the depressives with DST non-suppression, however this study had only 14/37 patients who were non-suppressors and the results did not reach statistical significance. In a study of life events using the LEDS with 72 depressed patients, Dolan et al. (1985) found that depressed patients who had experienced severe life events or difficulties had higher urinary free cortisol than the group of depressed patients who had not had life events. In contrast to the studies mentioned so far Jacobs et al., (1984) looked at mainly elderly subjects. They interviewed spouses, of married persons between 45 and 80, who had recently been admitted to hospital because of a life threatening physical illness. In 53% of the cases the hospitalised spouse died within two



months after admission. Jacobs et al. (1984) found that elderly persons under stress excreted more urinary-free cortisol than did the middle aged group.

When potentially confounding factors were controlled for the association between age and cortisol was accentuated for those with more severe depression.

Roy et al., (1988) found a significant correlation between urinary-free cortisol and urinary outputs of noradrenaline and VMA, its metabolite, in depressed patients but not in normal controls. They suggest that this finding consolidates previous work indicating that dysregulation of both the hypothalamic-pituitary-adrenal axis and noradrenergic systems can occur in depression. Roy et al., (1986) also looked at hypercortisolism and CSF monoamine and monoamine metabolite levels in depressed patients. They found that patients who had not had a recent life event in the six months before the onset of depression had significantly lower levels of the dopamine metabolite HVA and the 5HT metabolite 5-HIAA than those who had a recent life event. It was suggested that the presence or absence of life events *'led to a separation into biologically distinct groups'*. This is interesting because decreased levels of CSF HVA and 5-HIAA are also found in Alzheimer's disease (Blennow et al., 1991) and may reflect *'cerebral degeneration in Alzheimer's disease'*, even though as has been stated decreased levels can also be found in depression.

Checkley (1992) reviewed the possible ways neuroendocrine mechanisms might be involved in the precipitation of depression by life events. He concluded that life events could act by way of noradrenergic projections from the brainstem to the hypothalamic pituitary axis and so the secretion of Corticotrophin Releasing Factor, ACTH, corticosteroids, and the actions of corticosteroids at type II corticosteroids receptors in the brain. In support of an interaction between glucocorticoids and depression, Checkley (1992) goes on to argue that the increased risk of depression in Cushing's disease may be related to the effects of high plasma cortisol and low plasma ACTH, particularly since lowering of the plasma cortisol and elevation of the ACTH reduces the severity of the depressive symptoms (Jeffcoate et al., 1979). This is supported by the finding that

activation of the corticosteroid type II receptors is involved in the development of learned helplessness (Veldhuis et al., 1985). Since life events are not only associated with depression, they must have a general rather than a specific stressor effect and the neuroendocrine changes suggesting possible mechanisms for their action maybe applicable to the mechanism of action of life events in other disorders. This theory has been supported by a study of initially healthy elderly people in which serum cortisol significantly increased after a stressful life event (Willis et al., 1987).

HPA axis dysfunction may also influence genetic predisposition to illness. Increased corticosteroids bind to type II corticosteroid receptors in the limbic region of the brain including the noradrenergic and serotonergic projections to the forebrain. Corticosteroid receptors are intracellular and when bound to corticosteroids are translocated into the cell nucleus where they bind to DNA and activate the transcription of MRNA (Beato, 1989), suggesting a possible genomic link between genetic predisposition and the effects of life events (Bebbington and McGuffin, 1989). In this way corticosteroid levels could interact with a genetic propensity leading to a psychiatric disturbance such as dementia or depression.

Stressful life events can also impair the function of the immune system (Irwin et al., 1987; Willis et al., 1987, Schleifer et al., 1983). Syvälahti (1987) reviews the interaction between the endocrine and immune systems in stress and concludes that there is much evidence to suggest that in addition to autoregulation the immune system is also *'under external regulation, especially by the endocrine and neural systems'* and that stressful life events can impair immune function and so increase an organism's vulnerability to disease states. Leonard (1990) states *'there is now a sufficient body of objective evidence to link stress-induced behavioral changes with immunological deficits and susceptibility to physical illness'*. Leonard (1990) argues that the mechanism of mediation for the immune system is through the hypothalamo-pituitary axis and this is likely since high cortisol levels also suppress the immune system.



### **Psychiatric disorder, age, and HPA axis dysfunction**

The dexamethasone suppression test (DST) is used to test if cortisol levels are responsive to suppression by dexamethasone. In an individual with normal negative feedback control (working through the HPA axis) dexamethasone suppresses cortisol output and so lowers plasma cortisol. Non-suppression after dexamethasone is found in 40-60% of depressed patients (Carroll et al., 1981). Although some researchers have suggested that it is a valid marker for 'endogenous' depression (Zimmerman et al., 1986), this is unlikely because it is often abnormal in 'neurotic depression', schizophrenia (Powchik et al., 1987), dementia (Katona and Aldridge, 1985; Alexopoulos and Abrams, 1991; Lawlor et al., 1992), other psychiatric conditions and in a small proportion of normal healthy controls (Sashidharan, 1984). Among non depressed patients with Alzheimer's disease 33% to 50% of have DST non-suppression (Georgotas et al., 1984; Alexopoulos and Abrams, 1991) and elevation in basal cortisol levels has also been demonstrated (Raskind et al., 1982).

As the DST appears to reflect malfunction of the homeostatic mechanisms of the stress control response, this suggests that depression and Alzheimer's disease may share abnormalities in the HPA axis (Alexopoulos and Abrams, 1991). The hippocampus is one of the primary sites of neuropathology in Alzheimer's dementia and as discussed earlier is principle component of the HPA axis. It may be tempting to speculate that a primary hippocampal lesion may be responsible for HPA axis dysfunction. However, this is unlikely since at least 50% of Alzheimer's disease patients do not exhibit hypercortisolaemia. It is interesting to see that the variability in HPA function is also associated with patient age i.e. older patients with AD have a higher incidence of dexamethasone resistance (Greenwald et al., 1986).

### **Aging and HPA axis function**

There is considerable evidence from animal studies to suggest dysregulation of the HPA with increasing age. Aged rats show increase in basal activity of HPA function resulting in increased plasma levels of ACTH and corticosteroids (Sapolsky et al., 1983a). The aged rat is also dramatically impaired in its capacity to terminate the stress response.

Corticosterone in aged rats remains elevated for as long as 24 hours post stress (Sapolsky et al., 1986b). In addition they show delay in adapting to mild sustained stress. This increase in HPA activity appears to be a manifestation of diminished glucocorticoid feedback on HPA function: aged rats show reduced HPA suppression following exogenous treatment with either corticosterone (Dilman, 1981) or dexamethasone (Sapolsky and Altman, 1991). Primate studies have also demonstrated increases in basal cortisol with age. Interestingly, this elevation was non-progressive emerging abruptly in the most aged quartile (Sapolsky et al., 1983b). Sapolsky (1986b) suggests that there is a greater degree of neuroendocrine redundancy in the primate hippocampus with the emergence of hypersecretion only in extreme old age.

The evidence for a syndrome of glucocorticoid hypersecretion as a function of normal ageing in humans remains controversial. Carroll et al. (1981), who initially described the dexamethasone suppression test in psychiatric illness, found a non-linear relationship between age and abnormal DST suppression, with a higher prevalence of cortisol non-suppression in middle life. Okenkrug et al. (1983) have reported a significant contribution of age to the variance of post-dexamethasone cortisol levels in normal subjects following 0.5mg of dexamethasone. Differences in cortisol levels after 1mg of dexamethasone did not reach statistical significance, however (Tourigny-Rivard, 1981). Sapolsky (1986b) argues that the age groups studied traditionally reflect the 'younger' aged. Thus when 80 and 90 year olds are studied, higher rates of hypercortisolism and dexamethasone resistance occurs. A recent study by Dodt et al., (1991) comparing elderly Alzheimer's patients with young and elderly fit control groups found no difference in basal cortisol levels between the three groups. Both elderly groups had higher basal ACTH levels compared to the young controls. However, after administration of CRF/lysine vasopressin, the peak ACTH and cortisol levels were similar in the young controls and Alzheimer's patients but higher in the fit elderly. Moreover, only the dementia patients had a delay in the post-stimulus decline in ACTH levels. These results suggested an enhanced reactivity of the feedback mechanisms of the HPA axis in the mentally fit elderly probably due to diminished sensitivity to negative feedback via glucocorticoids. This reactivity was



attenuated in Alzheimer's disease (AD) patients indicating alterations in the HPA axis. Dodt et al., (1991) point out that there is only sparse data about the function of the HPA axis in AD. They suggest that since studies have observed CRF depletion in the cerebral cortex of AD patients (De Souza et al., 1986) and acetylcholine may be involved in CRF regulation, the loss of cholinergic neurons (in the hippocampus) as occurs in AD may be a mechanism whereby HPA function is disturbed.

Although an effect of age on HPA axis function in normal humans has not been proven, age, when compounded by disease processes such as depression and dementia, may produce significant effects on HPA function. In other words, if age coincides with a disorder of borderline glucocorticoid resistance, the two combine to elevate the incidence of its occurrence. Thus, in depressive patients, dexamethasone resistance becomes more prevalent with age. Georgotas et al (1984) found that 83% of depressives aged greater than 60 years were DST resistant. Sapolsky et al (1986a) suggest that stressors may contribute to resistance to negative feedback regulation in these patients, by mediating transient down regulation of glucocorticoid receptors in the hippocampus. They suggest that the 'normative impairment' of the aged hippocampus (usually below threshold for disturbance of HPA function) and the 'impairment' due to the depressive or stressed state can summate to produce overt HPA dysfunction.

The relationship between dementia, hypercortisolism and depressive symptoms remains unclear. Some studies have found more depressive symptoms in DST non-suppressors with AD (Katona and Aldridge, 1985) whereas other studies have not found a link with depressive symptomatology (Lawlor et al., 1992) except for symptoms of agitation (which does not necessarily imply a depressive syndrome). There also appears to be no obvious relationship between severity of dementia and DST non-suppression (Katona and Aldridge, 1985; Lawlor et al., 1992). Nevertheless, the abnormal DST results in around 50% of AD patients is one indication of HPA axis dysfunction.

In summary, life events appear to be able to produce changes in hypothalamic-pituitary-adrenal axis function such as hypercortisolism, and may also impair immunity. Depression and dementia in the elderly appear to have similar neuroendocrine changes in terms of CSF monoamine metabolites and hypercortisolism. This suggests that psychosocial stressors and biological systems may be closely linked and also provides the beginnings of a theoretical explanation for other studies which indicate that life events can precipitate other illnesses.

### **Hippocampal pathology and HPA axis function**

As discussed, there appears to be an emergence of glucocorticoid hypersecretion with age, particularly in aged rats. The mechanism for this process has been the subject of extensive research. Sapolsky et al. (1990) have previously demonstrated both hippocampal neuronal loss and loss of glucocorticoid receptors in the ageing hippocampus. The aged hippocampus loses approximately 50% of glucocorticoid binding sites (Landfield et al., 1978) a loss which appears to be restricted exclusively to the neuronal receptor population and is, at least in part, due to death of the target neurones (Sapolsky and Plotsky, 1990). This progressive hippocampal degeneration with age has been shown to be significantly contributed to by adrenal hypersecretion in aged rats. Increased exposure to adrenal glucocorticoids appears to be associated with the loss of hippocampal neurones. In aged rats, the degree of hippocampal neuronal loss is positively correlated with increase in adrenal activity (Landfield et al., 1981). Moreover, in rats with normal glucocorticoid function, adrenalectomy in mid-life retards the process of hippocampal loss (Sapolsky et al., 1985), while prolonged exposure to high (physiological) concentrations of glucocorticoids appears to exacerbate it (Sapolsky, 1990). In other studies, chronic stress has been shown to cause premature ageing changes in hippocampal electrical activities (Kerr et al., 1986). Persistent stress prenatally also results in abnormal neuronal development in foetal hippocampus (Uno et al., 1989a).

The mechanism of glucocorticoid mediated neurotoxicity is not clear. It may be a direct effect. However, Sapolsky (1990) has suggested that levels of glucocorticoids may act



indirectly, by exacerbating hippocampal damage due to a variety of other insults, by disrupting hippocampal glucose utilisation. These studies suggest that, in the rat, stress, acting via glucocorticoid secretion, may accelerate hippocampal neuronal loss, that occurs both as a function of "normal" ageing and during varied insults such as hypoxia, ischaemia, or seizure (Sapolsky et al., 1986a).

Similar findings are emerging in primate studies. The primate hippocampus loses neurones with age in a distribution similar to the rat (Coleman and Flood, 1987). Uno et al (1989b) demonstrated marked hippocampal degeneration in vervet monkeys subjected to sustained social stress. Prolonged exposure of foetal rhesus monkeys to high concentrations of synthetic glucocorticoids caused hippocampal damage (Uno et al., 1983). In a further study, sustained exposure to locally applied glucocorticoid caused hippocampal damage similar to glucocorticoid induced toxicity in the rat hippocampus and stress-induced toxicity in the primate hippocampus (Sapolsky et al., 1990).

Although stress is a potential aetiological factor in the HPA axis dysfunction found in depression there have not been comparable studies looking at stress in Alzheimer's disease. The potential interaction between stress, hypercortisolaemia and dementia is, therefore, more difficult to assess. Evidence for potential glucocorticoid mediated neurotoxicity in humans is sparse. Older literature examining post-mortem status of brains of individuals with Cushing's syndrome reports a low but consistent incidence of neural atrophy (Trethowan and Cobb, 1952). Torture victims have also been reported to have high incidence of cerebral atrophy, ventricular enlargement and dementia (Jensen et al., 1982; Thygesen et al., 1970). There is some evidence for a correlation between hippocampal damage and glucocorticoid hypersecretion. Chronic alcohol exposure, which reduces hippocampal neuronal number, is associated with hyperactivity of the HPA (Walker et al., 1980; Pohorecky, 1981). Conversely, stimulation of the human hippocampus has been reported to cause inhibition of adrenal secretion (Mandell et al., 1963).

### **Hippocampal damage and cognitive impairment**

Morris et al. (1982) have shown that in young animals hippocampal lesions are associated with spatial cognitive impairments. Not all aged rats show cognitive impairment, and in a recent study (Issa et al., 1990) cognitive impairment occurred in around 30%. The cognitively impaired rats were found to have more pronounced loss of hippocampal neurones. More specifically, the study found elevated HPA activity correlated with the presence of cognitive dysfunction. Although both control and subject animals showed reduction in hippocampal corticosteroid receptor numbers, the cognitively impaired group showed a significantly greater loss. Patients with hypercortisolism due to Cushing's disease also often show a range of cognitive impairments (Whelan et al., 1980) and cerebral atrophy (Momose et al., 1971) although this may be reversible with treatment (Lishman, 1987).

Issa et al. (1990) reviewed the possible relationship between senescent HPA overactivity and hippocampal pathology and memory deficits. Among aged rats the degree of hippocampal neurone loss and memory deficit correlated with adrenal activity (Landfield et al., 1981). Animals adrenalectomized in mid-life, in addition to showing reduced neuronal loss, show improved cognitive functioning compared to control animals (Sapolsky et al., 1985).

### **Aging, dementia and the 'Glucocorticoid Cascade Hypothesis'**

In an attempt to integrate these findings Sapolsky et al. (1986a) proposed a glucocorticoid dependent component of brain ageing known as the 'Glucocorticoid Cascade Hypothesis'. They suggested that periods of stress and of excessive cortisol secretion may lead to transient down regulation of corticosteroid receptors which "corrects" once the period of hypersecretion terminates. However, at some point the self-correction fails, leading to persistent down-regulation of receptors, further increase in corticosterone secretion, and consequently, further down regulation of receptors. These combine to form a "feed forward" cascade exacerbated by receptor loss and frank neuronal loss due to the toxic effects of high corticosteroid levels. This in turn results in further augmentation of the



cascade effects. The model demonstrates how stress may interact with the ageing process, exacerbating hippocampal damage and potentiating cognitive impairment.

Recent research provides some support for the 'Glucocorticoid Cascade Hypothesis'. Rat basal glucocorticoid concentrations tend to rise with age (Sapolsky, 1991) although the aged pituitary shows a dampened response to CRF, and, the aged adrenal has a reduced response to ACTH (Hylka et al., 1984). Although the aged rat may be able to appropriately initiate a stress response it is dramatically impaired in its ability to terminate it (Sapolsky et al., 1983b). This causes corticosteroid hypersecretion which leads to corticosteroid receptor loss and damage and also destruction of hippocampal neurons (Sapolsky et al., 1985; Sapolsky, 1986a). The progressive hippocampal degeneration with age has been shown to be worsened by adrenal hypersecretion (Sapolsky and Plotsky, 1990).

Sapolsky et al (1986a) have postulated that AD and age interact to cause HPA dysfunction. Thus, in younger patients with AD dexamethasone suppression is intact, suggesting that the degree of hippocampal damage due to AD is insufficient to cause frank HPA dysfunction. In older patients however, age related hippocampal impairment combines with AD induced damage to produce overt HPA impairment. A further development of this hypothesis is to suggest that the initially mild hypercortisolism produced as a consequence of this interaction further sensitises hippocampal neurones to the pathology of AD, producing a model similar to the Glucocorticoid Cascade Hypothesis proposed by Sapolsky et al. This allows one to understand a mechanism by which stress can accelerate, or contribute to the ageing process and Alzheimer's Disease.

## **Conclusion**

The current clinical, pathological and aetiological models of Alzheimer's Disease do not provide an adequate explanation for the wide variations in the course of the disorder or the cause of the disorder in the majority of sufferers. Neuroendocrine changes suggest a possible bridge between ageing, genetic predisposition, stress and history of depression

in the aetiology of AD. This is interesting in the light of recent studies which suggest that a past history of depression may be a risk factor for the later development of Alzheimer's disease (Amaducci and Lippi, 1992).

Animal studies suggest a potential feed forward cascade between loss of glucocorticoid receptors and hippocampal neurones as a result of glucocorticoid excess (due to intrinsic hypersecretion, stress or exogenous administration) which the ageing hippocampus is less able to inhibit. The resultant HPA overactivity has been correlated with cognitive impairment in rats. Studies in humans suggest that this model, if present, acts at a much higher threshold. Nonetheless, emerging evidence suggests that there is a syndrome of mild overactivity in the HPA with increasing age. The coexistence of ageing and a syndrome of glucocorticoid resistance, notably depression or Alzheimer's Disease can lead to the emergence of significant HPA dysregulation. Stress can lead to neuroendocrine changes involving the HPA axis. Stress and hypercortisolism may also be associated with adverse effects in related cholinergic and/or noradrenergic systems. Therefore, this model provides a potential mechanism whereby stress, by increasing glucocorticoids, may further exacerbate the effect of "normal" ageing and potentially precipitate or exacerbate dementia. In this way it also provides a potential link between environmental stressors, such as life events, and the neurobiology of ageing and dementia.



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## Life events: the reliability of rating changes in routine and environment

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**Summary.** Alterations in routine and environment can affect clinical state in patients suffering from cognitive impairment. A method for rating life events for changes in routine and environment is described and found to be highly reliable even when used by inexperienced raters after brief training.

Life events have been shown to make an important contribution to the onset or relapse of conditions such as depression and schizophrenia (Brown and Harris 1978; Brown and Birley 1968). More recently they have also been linked with the onset of depression in the elderly (Murphy 1982; Linn et al. 1980). Life events have been frequently linked with the decline in physical health or the subsequent death of an individual (Rowland 1977; Brown and Harris 1989). In addition they are associated with an increased likelihood of contacting medical services in response to a physical problem. There is however a dearth of studies examining life events in relation to organic psychiatric disorders such as senile dementia. Such studies are needed, since it is well known that those suffering from cognitive impairment are not only sensitive to changes in their daily life but also experience distress. Thus Bicknell (1983) emphasises the importance of understanding the impact that life events can have on mentally handicapped people.

Life events have been rated according to many different potential attributes (Brown 1989). However the scales so far employed have not been ideally suited for use with cognitively impaired patients. Such subjects may be less aware of what is going on, and on the other hand deterioration in their mental state could be attributed to a disruption in their daily life which has distressed or confused them. Dementia patients often find changes in their social routine or perceptual environment difficult because their cognitive impairment limits their capacity to adapt.

A variety of studies have indicated that dementia patients are sensitive to changes made in their ward routine and environment (Melin and Götestam 1981; Stahler et al. 1984; Cosin et al. 1958). A recent case-controlled prospective study, looked at the effect of an enforced move on dementia sufferers (Anthony et al. 1987) as a result of the closure of a large psychiatric hospital and the relocation of the patients to smaller units in two general hospitals. A large proportion of the sample showed significant depressive behaviour following transfer and a significant degree of disturbed behaviour and disorientation remained after the move. An earlier study (Crank and Zweig 1980) showed a significant increase in mortality amongst dementia patients after relocation following a hospital closure. Reality Orientation therapy indicates that assisted focus can help to reduce the confusing elements in the environment with a resulting improvement in functioning (Holden and Woods 1988). The corollary is that changes in the patient's routine or environment occasioned by an event such as a move or the death of someone in close contact with the patient might alter their social resources in such a way as to overload coping skills, already impaired by cognitive deterioration. It is ironic that life events were originally rated for 'changefulness', that is, the extent to which they involved a change in the subject's routine (Holmes and Rahe 1967). It was only later that they were rated in terms of stressfulness or their degree of threat (Bebbington 1987). Contemporary methods of rating life events assess threat but only take account of change in daily life indirectly. Although Brown and Harris (1978) introduced a variety of other dimensions including one measuring 'routine', these were unsuitable for the purposes of our study.

The purpose of the current study is to introduce new, specific and operationally defined dimensions for rating life events in terms of changes in 'environment' and 'routine' which will have relevance for evaluating their impact on patients who are cognitively impaired. We present evidence of the reliability of these new scales. We hope to



demonstrate that these dimensions of routine and environment can be reliably rated by inexperienced raters after brief training based on written guidelines.

## The Scales

These scales were developed to measure changes in the subject's social routine and perceptual environment, as part of a larger study investigating life events preceding deterioration in patients suffering from senile dementia. The new scales of change in 'routine' and 'environment' are designed to measure the impact of an event on an individual's daily life, in particular its effect in causing confusion. Certain events may be judged to have no direct relationship to daily life, but may still be 'independent' (of an individual's sphere of influence) and involve a high degree of 'threat' to that person's wellbeing. An example of this might be the death of a sibling with whom the subject now has little or no regular contact except by letter or telephone. Such an event would involve a 'threat' but no change in the subject's regular routine or immediate environment. Likewise, disruption in the environment or routine of an individual's daily life may not involve a life event of measurable threat. Routine and environment are therefore measures that are quite distinct from the 'threat' attributable to a life event.

Change in routine is primarily concerned with personal contacts in the subject's day to day, life such as regular visitors. These would include for instance, a Home Help or other support staff such as a Warden. If one of

**Table 1.** Routine change – examples and rating scale

4 = Extreme	– Permanent loss of carer living with subject
3 = Severe	– Loss of carer attending 3 or more days per week or closure/loss of day centre. Duration – two weeks or more
2 = Moderate	– Loss of carer or visitor attending 1 or 2 days per week or loss of days attendance at a day centre. Duration – one month or more
1 = Mild	– Loss of any other visitor/carer/friend with whom the subject has regular contact (weekly). Duration – one month or more
0 = No change in routine	

**Table 2.** Environment change – examples and rating scale

4 = Extreme	– Moving to worse accommodation or a new area unknown to subject
3 = Severe	– Any other permanent or long term move (one month or more)
2 = Moderate	– Temporary move e.g. holiday, respite care, hospitalisation, or stay with relatives, for more than three days and less than one month
1 = Mild	– Changing to a different room in the home. Major structural alteration or damage in the home. Loss of regular visiting to another environment (for example day centre), for one month or more
0 = No change in environment	

these key people stopped attending, through illness or a change of job for example, it would constitute a routine change the severity of which would be determined by the relationship to the subject and contribution to the subject's routine. Regular structured activities outside the home such as attendance at a day centre or luncheon club are also rated. Changes in environment might involve a move, a holiday etc. or even major structural damage or repairs to the home. If the subject regularly spent a substantial proportion of the week in another place such as a day centre or someone else's home, then a change in this could also be regarded as a change in environment, the rating of which would depend essentially on the time spent there. Sometimes changes in environment and routine will occur together, for example the closing of a day centre which the subject had been attending. The points of the scales are shown in Tables 1 and 2.

## Hypothesis

Changes in the individual's routine or environment occasioned by life events can be reliably assessed using simple scales and guidelines after the rater has received a brief training.

## Method

The life events experienced by 25 elderly senile dementia patients in the six month period prior to their admission to hospital were elicited from a close informant. A history of life events was also elicited from 25 fit, control subjects, age and sex-matched from a local general practice population. The interviews were based on the Bedford College Life Events and Difficulties Schedule (Brown and Harris 1978).

Guidelines for rating changes in routine and environment were drawn up, and ratings of life events were then made (PB and MWO). In order to investigate the reliability of life event ratings based on the use of the revised guidelines, two inexperienced raters were recruited (NE and JO). Both of the raters were psychiatric registrars at the Maudsley Hospital with at least a year's experience in psychiatry, including psychogeriatrics. Neither was familiar with the two new scales, or had experience of rating life events.

The new raters were given the guidelines to read in advance, together with a series of subject vignettes (a mix of patients and controls) giving an outline of the physical health and social situation of each subject (see Appendix 1 for an example). In particular, the relatives, friends, other carers and support services were mentioned. The raters were blind to the subject's psychiatric status. Descriptions of six life events were provided with details of all the ratings made (threat, independence, routine and environment).

A training session of 45 min then took place, during which the principles of the guidelines and the rating of the examples were discussed. In the latter part of the session the raters (NE and JO) were given a further 6 life event



examples to consider, and asked to rate them for changes in routine and environment. At the end of the training session, the raters discussed their results with the trainer (MWO) who clarified any discrepancies so that a consensus on the ratings was achieved.

The new raters were then given copies of more subject vignettes, comprising 30 life events to rate for routine and environment change (some subjects had experienced more than one life event). They were provided with the ratings for threat and independence for each event, but once again were blind to whether the subject was a patient or control. The raters were instructed not to confer.

All 30 life event ratings were completed by both novice raters. Standard ratings were been made by one of the experienced raters (PB) who was blind to all previous ratings. The ratings of PB were then used as the benchmark comparison for ratings of routine and environment change.

## Results

Reliability was assessed by three comparisons of the 30 observations which each rater made for each scale (Tables 3 and 4).

- Between the experienced rater (PB) and each of the naive raters.
- Between the two naive raters.

The results were subjected to a computer program for assessing inter-rater reliability using weighted KAPPA (Cicchetti 1976). This statistical test was recommended by Hall (1974) because it is distribution free and allows credit for partial agreement. He proposed the use of weighted KAPPA (Cohen 1968), a statistic which has now been widely acknowledged as suitable for assessing reliability between raters.

The most important judgement was whether a life event implied any degree of change or not, rather than between mild, moderate and severe change. Because of this the distinction between 0 (no change) and 1 (mild change) was given a double weighting in the analysis. A  $\kappa$ -value of 0.8 or more is accepted as an excellent degree of reliability between raters. The results for environmental change and routine change are shown in Tables 3 and 4. Most of the re-

sults were above 0.8, and all were above 0.65. Good reliability was therefore obtained between both experienced and naive raters after brief training. Examination of the discrepancies between the raters suggest that they sometimes arose because some of the descriptions of the events were ambiguous. Reliability is dependent on the clear specification of events and with care might therefore be further improved.

In most cases however, discrepancies were the result of one of the raters failing to follow the guidelines correctly, despite adequate information. This suggests that reliability would also be improved by additional emphasis on following the guidelines during training.

## Conclusion

The new scales will permit reliable testing of the hypothesis, consistent with clinical experience, that alterations in routine and environment may be important factors affecting both the clinical state and the process of referral in patients suffering from cognitive impairment. The ratings form part of the study of life events in senile dementia currently being carried out by the authors. This should clarify the value of the new scales as a research tool for understanding how the effects of life events are mediated.

This study has established the preliminary requirement that the new scales are reliable, even when used by inexperienced raters after only brief training. Reliability would be improved by closer adherence to the guidelines and a more accurate recording of the time and duration of the social routine and perceptual environmental changes that occur with a life event.

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## Appendix 1

### Example A

87-year-old lady who lives alone in a rented flat. Her left leg was amputated 10 years ago and she gets phantom pains. Her son lives nearby and sees her every weekend. She has a home help twice a week but otherwise has little social contact.

*Life event.* An elderly lady who had been a close friend of hers for many years wrote to say that she had found out she had cancer of the bowel and would not be able to take a holiday because of it. Although they kept in touch they did not see each other regularly.

Severe threat

Independent

No change in environment ( $E = 0$ )

No change in routine ( $R = 0$ )

*Life event.* She had to go into hospital for five weeks for investigation of the phantom pains. No particular cause or improvement in treatment was found.

Moderate threat

Independent

Moderate change in environment ( $E = 2$ )

Mild change in routine ( $R = 1$ )

Table 3. Environment change

	Kappa	P
Comparisons:	PB and NE - 0.73	0.00001
	PB and JO - 0.86	0.00001
	NE and JO - 0.85	0.00001

Table 4. Routine change

	Kappa	P
Comparisons:	PB and NE - 0.67	0.00002
	PB and JO - 0.81	0.00001
	NE and JO - 0.83	0.00001



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